Parents' perceptions and experiences of parent-mediated intervention:

A qualitative approach

A thesis submitted in partial fulfilment of the requirement

For the degree of

Master of Arts in

Child and Family Psychology

In the

College of Education, Health and Human Development

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University of Canterbury

March 2020

ACKNOWLEDGEMENTS

First of all, I would like to thank Dr. Hannah Waddington and her research team for providing me with this unique opportunity to work with data they gathered through the experimental research. Early Start Denver Model (ESDM) has been an inspiration for my professional journey, and it was a great pleasure learning and understanding how parents experience ESDM-based parent-training and direct-therapy.

I would like to thank my supervisors Dr. Karyn France and Dr. Laurie McLay. I am incredibly grateful for the opportunity to work with both of you. Your guidance has been invaluable to me. For Karyn, it was a true privilege to have you as my supervisor. I am deeply appreciative of your unconditional positive regards, kind encouragement, patience and wisdom.

Last but not least, a heartful thanks to my family and friends for their endless support and encouragement. Without you, I would not have been able to make it through this journey. I feel incredibly lucky to have you in my life and also extremely grateful that I have you.

ABSTRACT

Parent Mediated Intervention (PMI) is a type of early intervention that provides systematic training in evidence-based intervention techniques to support parents to deliver therapy for their child with ASD. PMI is found to be one of the most cost-effective and ecologically validating approaches, where the role of parents is advocated and maximised. In the past few decades, much research has been undertaken to examine the effectiveness of PMI. However, there has been little research into how parents perceive and experience PMI. The two studies in this thesis addressed this gap by providing a qualitative systematic review and synthesis of parents' perceptions of PMI (Study 1), and a qualitative analysis of parents' experiences participating in ESDM-based parent training and low-intensity direct therapy (Study 2).

Study 1: Qualitative systematic review and synthesis of parents' perceptions of PMI

Objectives: First, to identify and synthesise the factors that facilitated or challenged parents' engagement in the parent-training component of PMI, and second, to evaluate the perceived outcomes of PMI from the perspectives of parents.

Method: A systematic search of qualitative studies relating to parents' perceptions and experiences of PMI for children with ASD was undertaken. Databases searched included Psych Info, MEDLINE, PubMed and Scopus. The Mixed Method Appraisal Tool (MMAT) was used to assess the methodological rigour of the studies, and thematic analysis was employed to synthesise the findings of the included studies.

Results: A total of 358 studies were identified, and 15 studies met the inclusion criteria. Of the 15 studies, one was excluded as it failed to meet the two screening criteria outlined in the MMAT. Three main themes and ten subthemes were identified: (1) facilitating factors *(therapist factors, flexibility and accessibility and benefits of a group-based format),* (2) perceived barriers *(difficulty coping with programme demands, circumstantial challenges,*

unmet needs of parents), and (3) perceived outcomes *(acquisition of knowledge and skills, changes in parents' perception of their child and themselves, improved sense of well-being and improved parent-child relationship).*

Conclusion: Two main conclusions were drawn from the findings. Firstly, the provision of PMI may benefit from establishing positive parent-therapist relationship, providing flexible scheduling and convenient location, supporting parents' emotional wellbeing and using a group-training format. Secondly, the theme *perceived outcomes* suggested that the positive impact of parent-training may occur at three levels. At first, parents gain new knowledge and skills through training. This then helps them to change the way they see themselves and their child, improve their interaction with their child and increase their sense of wellbeing. As a result, the relationship between parents and their child improves.

Study 2: Qualitative analysis of parents' perceptions of ESDM-based parent-training and low-intensity direct-therapy

Background: This study explored parents' perceptions and experiences of participating in ESDM-based parent-training and low-intensity ESDM direct-therapy. The data was gathered by an external research team as a part of their experimental research. A semi-structured interview was used to collect the data, and the verbatim transcripts of the interviews was provided for the purpose of this study.

Objectives: This study had two key objectives. The first was to understand how parents perceive ESDM-based parent-training and low-intensity direct-therapy. The second was to identify parent's preference between the two interventions approaches.

Method: The interview transcripts of four parents of young children with ASD were analysed using a qualitative content analysis.

Results: Parents were highly satisfied with ESDM-based parent-training and perceived that the training was beneficial for both parents themselves and their child. Parents were particularly satisfied with the location, handouts, supports for child-care during training, flexibility, personal and professional characteristics of the trainer, parent-led training approach and valued their relationship with the trainer. Systematic and contextual barriers, and lack of fit between parents' learning style and training techniques were identified as the challenging aspects of the training. In relation to low-intensity ESDM direct-therapy, parents reported varying perspectives regarding the outcomes of the therapy. Parents were particularly satisfied with the location (home-based) and expressed a positive impression of the therapist. They all valued a positive parent-therapist and child-therapist relationship. The challenging aspects of the therapy included observing the sessions, rigidity in the structure and delivery of the therapy. Parents also indicated that they prefer balanced and constructive feedback from the therapist instead of receiving only the positive feedback. In relation to the comparison of two intervention approaches, most parents preferred parent-training over the direct-therapy.

Conclusion: The identification of the satisfactory and unsatisfactory aspects of ESDM-based parent-training and low-intensity ESDM direct-therapy provides insight into how the training and the therapy may need to be refined to address the needs of parents. Furthermore, parents' high level of satisfaction and their preference of ESDM-based parent-training suggest that providing training for parents to implement the ESDM techniques appeared to be more appropriate and beneficial than professionally delivered low-intensity early intervention.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

CHAPTER 1

INTRODUCTION

Autism Spectrum Disorder (ASD) is a pervasive neuro-developmental disorder characterised by atypical language development and social communication as well as restrictive and repetitive behaviours and/or interests (American Psychiatric Association, 2013). The use of the words 'spectrum' and 'pervasive' indicate that ASD has a multifaceted nature, in which the symptom presentation and severity varies across individuals. ASD is also a lifelong condition, and some individuals living with ASD may require lifelong interventions and support, depending on the severity of symptoms.

According to recent epidemiological research, the prevalence rate of ASD is increasing rapidly (Matson & Kozlowski, 2011; Williams, MacDermott, Ridley, Glasson, & Wray, 2008). Currently, the Centre for Disease Control (CDC) in the United States (US) estimated that the prevalence of ASD is 1 in 59 children, with a significantly higher rate amongst boys than girls (Baio et al., 2018). The reasons for the increasing prevalence rate are mostly unknown. Nonetheless the increase is expected to continue, which suggests that the demand for early intervention services for ASD will increase as well. It is however noted that there has been a shortage of adequate human resources to deliver early intervention for children with ASD (Jacobson & Mulick, 2000). Early intervention is found to be effective when it is delivered with a high intensity for a long period of time, which limits the number of clients that a therapist can see on a daily basis.

In order to address this, many researchers turn their interests to training significant figures in children's lives, such as parents or immediate caregivers. In response to this, parent-mediated intervention (PMI) has emerged as an approach in which parents are trained to deliver evidence-based early intervention to their child with ASD. PMI is systematically designed to train parents in a set of behavioural skills or techniques by a trained therapist or

clinician (Bearss, Burrell, Stewart, & Scahill, 2015). The ultimate goal of PMI is to enable parents to function as a primary therapist or co-therapist to deliver intervention for their own child (Leaf et al., 2017).

The development of PMI is centred around the notion that an "early, intensive and comprehensive intervention" is pivotal to promoting positive and valuable changes in the development of children with ASD" (Leaf et al., 2017, p. 109). Given the significance of parents in children's lives, it is possible to assume that parent-delivered intervention may lead to a longer-lasting treatment effect than therapist-delivered intervention alone (Ruppert, Machalicek, Hansen, Raulston, & Frantz, 2016). While most therapists can only work with a child for a few hours a week, in general, parents have far more time and opportunities to deliver intervention to their child through naturally occurring daily interactions. Consequently, involving parents can provide better continuity and enhance the therapeutic effect.

Currently, PMI is recognised as an empirically validated intervention approach for children with ASD and it has gathered significant research interest over the past few decades (Ingersoll & Dvortcsak, 2006; Leaf et al., 2017; Wainer & Ingersoll, 2013). Furthermore, PMI is recognised and incorporated as a necessary component in many early intervention approaches (Lang, Hancock, & Singh, 2016). In these approaches, parental involvement is considered to be imperative and collaboration between parents and therapist is seen as a key to treatment success (National Research Council, 2001). Although there is a limited evidence supporting the effectiveness of PMI or superiority of PMI against therapist delivered early intervention (Oono, Honey, & McConachie, 2013), some studies have demonstrated positive effects of PMI in improving parental functioning and family quality of life (Estes et al., 2009; Tonge et al., 2006).

Unlike the proliferation of research investigating the effectiveness and feasibility of PMI, however, there is a scarcity of research which explores parents' perceptions and experiences of PMI. According to the diffusion of innovation theory proposed by Rogers (2003), understanding how participating members perceive the acceptability and feasibility of the intervention is one of the most important elements that predicts therapeutic success. Given the level of involvement required for parents in PMI, it is even more important for researchers in the field to pay attention to understanding how parents experience PMI.

The primary purpose of this thesis is to provide an in-depth understanding of parents' perceptions and experiences of PMI. To achieve this purpose, two studies have been conducted. The first study (Study 1) is a qualitative systematic review and synthesis of the literature regarding parents' perceptions and experiences of PMI. The aim of the review is to explore the available evidence regarding parents' perceptions of PMI and to synthesise the experiences and perspectives of the parents.

The second study (Study 2) is a qualitative analysis of parents' perceptions of the parent-training and low-intensity direct-therapy based on the Early Start Denver Model (ESDM). In this study, parents' perception regarding a specific model of parent-training is explored. The data for the analysis is provided by an external research team led by Dr Hannah Waddington at Victoria University of Wellington. Within this research, a semi-structured interview was conducted with four parents of children with ASD after they received ESDM-based parent-training and low-intensity ESDM direct therapy.

By conducting two studies, the readers have been provided with a broad understanding of how parents perceive and experience PMI in general while also being introduced to a specific model of parent-training (ESDM-based parent-training). The comparison between the findings of these two studies may also provide additional and complementary information to enhance the delivery of PMI.

Organisation of the thesis

This thesis is composed of five chapters. In Chapter 1 (this chapter), a general overview and the purpose of this thesis is described. Chapter 2 is a literature review. The review provides a broad overview of the background concepts necessary to understand the topic of this thesis. In Chapter 3, a rationale for conducting the two studies is illustrated, followed by the description of an overarching methodological approach of the two studies. Chapter 4 presents Study 1, which is a qualitative systematic review and synthesis of literature regarding parents' perceptions of PMI. Chapter 5 presents Study 2, which is a qualitative analysis of parents' perceptions of ESDM-based parent-training and low-intensity ESDM direct-therapy. The contents of this thesis are illustrated in Table 1.1.

Table 1.1

Contents of this thesis

Chapter	Title	Contents
1	Introduction	This chapter provides the background to this thesis. The purpose and structure of the thesis are described.
2	Literature Review	This chapter serves two purposes: providing a conceptual overview of ASD, PMI and ESDM and addressing the need for exploring parents' perceptions of PMI. Firstly, the chapter begins with a general description of ASD and covers a historical overview of how the diagnostic concept of ASD developed. The changing understanding of the role of parents in the field of ASD research is discussed in relation to early intervention. Secondly, the conceptual overview of PMI is provided. The issues surrounding the term of PMI and its' effectiveness are discussed. The relative scarcity of qualitative literature regarding parents' perceptions of PMI is addressed at last. Finally, the concept of ESDM is provided with a specific focus given to Parent-implemented ESDM (P-ESDM). The effectiveness of P-ESDM and the lack of qualitative research regarding parents' perception of P-ESDM are discussed.
3	Rationale and Methodology	This chapter provides a rationale for conducting Study 1 and Study 2. Research questions for each study are outlined. The description

		and justification of the chosen methodological approach are presented as well.
4	Study 1	In this chapter, a detailed description of the method employed for the qualitative systematic review and synthesis is provided first. The result of the synthesis is illustrated and discussed.
5	Study 2	This chapter begins with providing study context describing where and how the data was gathered and provided for me to analyse. The detailed description of the method employed for the analysis, and the main findings are presented and discussed.

CHAPTER 2

LITERATURE REVIEW

Autism Spectrum Disorder (ASD)

Autism spectrum disorder (ASD) is a pervasive neuro-biological developmental disorder characterised by atypical language development and social communication, as well as restrictive, repetitive and stereotyped patterns of behaviours, activities or interests (American Psychiatric Association, 2013). The use of the term 'spectrum' indicates that ASD exists on a continuum where the characteristics and severity of the symptoms vary across individuals. That is to say, individuals with a diagnosis of ASD do not necessarily share similar behavioural difficulties or levels of functioning, and their impairments are not limited to a particular symptom or symptoms.

Currently, there is no official information regarding the prevalence rate of ASD in New Zealand (Ministry of Health and Education, 2016). However, a recent increase in epidemiological research documented an upward trend in the prevalence rate of ASD in other Western European countries (Matson & Kozlowski, 2011; Williams et al., 2008). In 2010, a national survey conducted by the Centres for Disease Control and Prevention (CDCP) in the United States (US) estimated an overall prevalence rate of ASD among eight-year-old children as high as 147 per 10,000 (Baio, 2014). In the same survey conducted in 2014, the estimate had increased to 168 per 10,000 (Baio et al., 2018). An Australian study which compared two birth cohorts of children born four years apart reported a higher prevalence rate of ASD amongst the later-born cohort (May, Sciberras, Brignell, & Williams, 2017). While the methodological challenges associated with the epidemiological studies of ASD prevalence question the validity of such findings, there are a few other factors which may account for the increased detection rate of ASD in young children. These include changes in

diagnostic criteria for ASD and the recent increase in the awareness of ASD amongst health professionals and the general public (Matson & Kozlowski, 2011).

ASD is considered a life-long condition with no known cure. The aetiology of ASD is one of the most poorly understood yet the most intricate of any other psychological or behavioural disorders. It is believed that the origin and the development of ASD is multifactorial in nature, suggesting that both biological and environmental factors contribute to the development of ASD (Durand, 2014). The variety in symptom presentation and the manifestation of ASD across individuals adds another layer of complexity to the work of scientists attempting to ascertain the exact cause or biomarker of the disorder. Despite such challenges, a substantial body of research has been conducted and proposed to ascertain the cause of ASD. More importantly, there has been an increase in the advances made in validating ASD as a diagnostic concept. This, in turn has facilitated the rapid development of assessment and treatment approaches to ASD (Volkmar, 2008).

The following is a brief historical overview of the diagnosis and definition of ASD which reflects how the field has evolved and developed.

Historical overview of ASD diagnosis

Autism and childhood onset of schizophrenia. The term ‘autism’ was derived from a Greek word ‘autos’ meaning ‘self’, and it was first used in the early 1900s by Eugen Bleuler, a Swiss psychiatrist and eugenicist (Scahill, Turin, & Evans, 2014). Unlike the current understanding of autism, Bleuler referred to autism to describe people with psychosis who showed a tendency to withdraw into inner reality while resisting or isolating from the outer world (Maye, Kiss, & Carter, 2016; Scahill et al., 2014). Therefore, autism was described only in relation to the symptoms of childhood-onset schizophrenia in the first and second edition of the Diagnostic and Statistical Manual (DSM) published in 1952 and 1968.

Kanner's infantile autism. The concept of autism that we are familiar with today was first introduced by Leo Kanner, a psychiatrist in United States, in 1943 (Adler, Minshawi, & Erickson, 2014; Bodea & Lubetsky, 2011; Scahill et al., 2014; Volkmar & Wiesner, 2017). He conducted a study with 11 children and identified the similar behaviours that did not meet the descriptions of other psychological disorders known at that time. Kanner published his work in a seminal paper called 'Autistic disturbances in affective contact' and used the term 'Infantile Autism' to describe the identified symptoms (Adler et al., 2014; Bodea & Lubetsky, 2011). In this groundbreaking work, Kanner described seven characteristics observed among children; "profound autistic withdrawal" (difficulty forming affective contact with others), "need for sameness" (extreme insistence on routine), "excellent rote memory", "mutism or language that lacks communicative purpose" (limited language acquisition and unitality including echolalia), "tendency to be overstimulated", "skillful relationship with objects", and "appearance of intelligence" (Adler et al., 2014, pp. 5–6).

In 1956, Kanner and his colleague, Leon Eisenberg, revised and modified the initial characteristics associated with autism and proposed two main criteria: "extreme self-isolation" and "obsessive insistence of the preservation of the sameness" (Wing, 1991, p. 104). The term 'extreme self-isolation' derived from the initial characteristic called the 'profound autistic withdrawal' and described as "the highest order" of all the symptoms associated with autism, suggesting that Kanner conceptualised autism as "a disorder of social relatedness" (Adler et al., 2014, p. 7). The age of onset was identified to be eighteen to twenty months old (Adler et al., 2014; Wing, 1991).

Although Kanner argued that his concept of 'autism' was unique and distinctive to schizophrenia in children, it caused considerable confusion amongst practitioners. As a result,

‘child schizophrenia’, ‘child psychosis’ and ‘autism’ were used interchangeably for years (Volkmar & Wiesner, 2017).

Asperger’s syndrome. The concept of Asperger’s syndrome was also developed at a similar time period. In 1944, Hans Asperger, an Austrian Paediatrician, used a term ‘autistic psychopath’ and described similar behavioural features of children that were comparable to the description of the ‘infantile autism’ proposed by Kanner (Bodea & Lubetsky, 2011). Unlike Kanner’s description of autism, Asperger reported that the children he observed appeared to have adequate or even advanced language skills but showed a marked difficulty in reciprocally interacting with others (Scahill et al., 2014). Interestingly, Asperger considered the observed symptoms as personality traits rather than a disorder as Kanner believed (Volkmar & Wiesner, 2017).

The work of Asperger went unnoticed until Lorna Wing, an English psychiatrist, acknowledged his contribution in her seminal paper called ‘Asperger’s syndrome: a clinical account’ in 1981 (Bodea & Lubetsky, 2011). Since then, there has been much debate regarding whether and how to recognise Asperger’s syndrome as a separate entity to autism (Mayes, Calhoun, & Crites, 2001).

Autistic Disorder and DSM-III-R. In the third edition of DSM (DSM-III), distinctive to schizophrenia, autism was first recognised and accepted as a formal psychiatric disorder (Maye et al., 2016). It was called ‘infantile autism’ and placed under the category of Pervasive Developmental Disorder (PDD) (American Psychiatric Association, 1980). The other disorders classified under the PDD were residual infantile autism, childhood-onset (CO) PDD, residual COPDD and atypical PDD. According to Volkmar, Reichow, Westphal, and Mandell (2014), the inclusion of autism in DSM-III was reflective of the work of Michael Rutter and the definition of autism proposed by the National Society of Autistic Children in Great Britain (NSAC). In 1971, Rutter and his colleague, Lawrence Bartak, proposed a new

set of criteria by synthesising the academic works and opinions proposed after Kanner's concept of infantile autism was first introduced; "delay in speech", "failure to develop interpersonal relationships", "ritualistic and compulsive phenomenon", and "onset before thirty months" (Adler et al., 2014, p. 8). In 1977, the NSAC presented a definition of autism which was characterised by disruption in the normative course of development, sensory processing, verbal and non-verbal communication (Volkmar et al., 2014). Although it was a major advance to include autism as a separate entity in the DSM-III, the use of diagnostic concepts such as 'residual autism' and 'COPDD' was of concern. For example, the use of term 'residual' conveyed the idea that some people may grow out of autism, and the emphasis on the 'pervasive' nature of social deficits in early years lacked insight into how the symptoms of autism may change over time as an individual grows older (Volkmar et al., 2014).

In response to this, a revised version of DSM-III (DSM-III-R) made considerable changes to the diagnostic criteria outlined in the previous edition (American Psychiatric Association, 1987). This included the change in the name from 'infantile autism' to 'autistic disorder', and the adaptation of a polythetic approach instead of monothetic approach to diagnosis (Adler et al., 2014; Volkmar & Lord, 2008). More criteria were created and grouped into three major categories: difficulty in social interaction, communication and ritual-like insistence to the sameness. They were arranged in developmental order (Adler et al., 2014; Volkmar et al., 2014). The change also included the removal of the age of onset, and the problematic diagnostic concept, such as the 'residual autism' and 'COPDD' (Volkmar & Lord, 2008; Volkmar et al., 2014). Although DSM-III-R made a significant improvement from the previous edition, there were some concerns regarding the significantly broadened diagnostic criteria and its differences to the pending revision of the International Classification of Diseases 10th edition (ICD-10) (Volkmar et al., 2014).

DSM-IV and ICD-10. With growing concern regarding the broad diagnostic criteria of the DSM-III-R and the need for convergence between the DSM and ICD systems, a large amount of multisite fieldwork for the DSM-IV was conducted by Fred Volkmar and his colleague in collaboration with the ICD-10 revision process (Bodea & Lubetsky, 2011; Volkmar et al., 2014). The work revealed that a reduction in the draft of the ICD-10 criteria resulted in a reliable diagnosis across clinicians with varying levels of experience (Volkmar & Lord, 2008). A modification was made to the original ICD-10 draft and it was proposed to both the DSM and ICD. In the DSM-IV, the term PDD was used as an over-arching diagnostic concept to include Autism, Asperger's disorder, Rett's disorder and Childhood disintegrative disorder as well. The term 'PDD not otherwise specified (PDD NOS)' was introduced to describe the social deficits that were not qualified for meeting any other PDD (American Psychiatric Association, 1994).

Autism spectrum and DSM-V. Since Lorna Wing introduced the work of Hans Asperger, there has been an ongoing quest for many researchers and clinicians to provide a differential diagnosis between Autism and Asperger's syndrome. This has proven very difficult due to the significant overlap between the two concepts (Freeman, Cronin, & Candela, 2002; Mayes et al., 2001) and as a result, many efforts have been made to convey the need for a dimensional as opposed to a categorical approach (Freeman et al., 2002). Lorna Wing is one of the pioneers who first conceptualised autism as a spectrum disorder by embracing the concept of autism and Asperger's syndrome in a dimensional manner (Scahill et al., 2014). From an epidemiological study conducted with 163 children of various developmental disabilities and delays in London, Wing and Gould (1979) found that there were varying degrees of impairment among children with limited interested in social interactions. In 1988, Wing proposed that the concept of 'early infantile autism' proposed by Kanner and 'autistic psychopath' proposed by Asperger were rather alike and claimed that

they are part of "continuum or spectrum of autistic disorder" (Wing, 1988, p. 92). She stated that the use of term continuum was to capture the complexity of the wide and varied presentation of symptoms of individuals with autistic disorder, and it was not to simply differentiate them based on the severity of symptoms.

The dimensional approach to conceptualising autism is reflected in the DSM-V in which autism, Asperger's syndrome and PDD NOS are subsumed under a single category of ASD (American Psychiatric Association, 2013). According to the Neurodevelopmental Working Group that led the process of the development of the DSM-V, the purpose of subsuming the three disorders into a single category of ASD was to reduce inconsistency in clinical diagnosis. The merging of categories also aimed to improve clinicians' decision-making processes without losing the sensitivity of the diagnostic criteria (Lohr & Tanguay, 2013). In the DSM-V, the social and communication domains were collapsed into one core category, while the domain of restricted and repetitive behaviours and interests remained as another core category. A criterion describing hyper- or hypo-reactivity to sensory input was included in the domain of restricted behaviours and interests, but the criterion of speech delay was removed in the social and communicative domain. This was a bold change, and the issues regarding the sensitivity and validity of the revised criteria are still up for debate (Lohr & Tanguay, 2013).

Early Identification and Early Intervention

Since Kanner first introduced the description of autism, there has been a rapid expansion of interests and knowledge, especially in relation to early identification of the behavioural characteristics associated with autism (Siller & Morgan, 2018). The progress in early identification of autism began in the 1980s, using both retrospective and prospective approaches (Boyd, Odom, Humphreys, & Sam, 2010; Dawson & Bernier, 2013). A retrospective approach refers to reviewing past videos of children who were diagnosed with

ASD to identify atypical or unusual behaviours as well as the absence of behaviours expected to occur at the corresponding age. Prospective approaches refer to observing and monitoring siblings of children with ASD. The early signs that are documented through such works are impairments in social and communicative skills, inability to process and respond to socially oriented-information appropriately, lack of affect atypical eye-contact, impaired joint-attention and symbolic play, as well as some repetitive and ritualistic behavioural tendencies such as hand flapping, rocking and toe walking (Boyd et al., 2010). These findings facilitated the development of screening tools to detect early signs of autism in infants and toddlers, such as the Quantitative Checklist for Autism in Toddlers (Q-CHAT), Modified CHAT (M-CHAT), the First Year Inventory, and the Screening Tool for Autism in Two-Year Olds (Boyd et al., 2010). However, it is important to keep in mind that screening does not necessarily lead to diagnosis, as the accurate identification of autism is yet to be fully developed (Boyd et al., 2010).

The progress in terms of early identification, coupled with the conceptualisation of autism under the developmental framework, made a considerable shift in viewing autism from "a lifelong condition with very poor prognosis to one in which significant gains and neuroplasticity is expected" with early intervention (Dawson & Bernier, 2013, p. 1456). More specifically, the rationale behind the development of early intervention is centred on the notion of developmental plasticity in young children (Jagan & Sathiyaseelan, 2016; Lang et al., 2016). Developmental plasticity refers to the sensitive period of brain development where the external environment plays a significant role in shaping and moulding neural structures and networks (Dawson, Ashman, & Carver, 2000). Providing early intervention for children during this sensitive period is thought to ameliorate the development of atypical traits associated with ASD, which in turn promotes positive and improved developmental outcomes in the long-term (Lang et al., 2016; Smith & Iadarola, 2015). The work of Lovaas (1987)

provided compelling evidence demonstrating the positive developmental outcomes of young children with autism who received an early behavioural intervention based on the principles of ABA. Since that time many researchers have replicated and expanded his research and reported positive gains associated with providing therapy early. However, the empirical evidence regarding the effectiveness of early intervention is still debatable. For example, Warren et al. (2011) conducted a systematic review of early intensive intervention and reported that the evidence to support its effectiveness is relatively weak, suggesting that the field of early intervention needs to establish more rigorous and systematic approaches to investigate the validity of early intervention. However, it is important to keep in mind that investigating the effectiveness of early intervention is a tricky task; the severity of the symptoms amongst children with ASD varies greatly, and observing a meaningful change in children with severe symptoms of ASD can be quite challenging (Camarata, 2014).

Despite the issues and controversy regarding its effectiveness, early intervention is generally regarded as being of critical importance for children with ASD and their families (Boyd et al., 2010; Machalicek et al., 2014). As children with ASD often require supports for a wide range of developmental domains, a variety of approaches to early intervention have been developed over the years (S. L. Harris, 1998; Jagan & Sathiyaseelan, 2016). These can be classified into a focused practice model (FPM) or a comprehensive practice model (CPM) of early intensive intervention. As the name suggests, the FPM refers to the interventions that adopt a specific and focused approach, while the CPM consists of multiple focused intervention components and targets various developmental domains of children with ASD (Boyd et al., 2010). Examples of FPM include early intensive behavioural intervention (EIBI), positive behavioural support programme for children with ASD, naturalistic intervention programmes using incidental teaching or milieu communication training, parent-meditated interventions based on the EIBI, and pivotal response training (PRT). The CPM is

generally thought to be more complex and intensive than FPM (Boyd et al., 2010). Examples of CPM are the Early Start Denver Model (ESDM), Early Social Interaction (ESI), Project DATA for toddlers, Walden Toddler Programme (WTP) and Children's Toddler School (CTS).

Currently, it is believed that for children who are at risk of and/or are diagnosed with ASD to make meaningful progress, early intervention should be (a) individualised to children and their families, (b) comprehensive in nature, (c) based upon the principles of ABA, and (d) intensive; that is, a minimum of 25 hours per week (Harris, 1998; National Research Council, 2001; Ministry of Health and Education, 2016)

Training for Parents of Children with ASD

Early misconceptions of the role of parents in children's ASD

When Kanner first introduced his observation of children with autistic traits, he included the descriptions of somewhat unusual parent-child interactions and autistic traits noticed in parents (Harris, 2018; Volkmar & Lord, 2008). For example, parents appeared to have above-average intelligence, and they were less likely to be interested in interacting with others. This led some clinicians to make the assumption that parents were a major contributor toward their child's autism. For example, it was once thought that children's disinterest in social interaction was viewed as a result of severe "emotional disturbances" as children failed to develop "a trusting relationship" with their caregivers (Marcus & Schopler, 1989, p. 337-338) The impaired parent-child relationship was thought to be the main reason for this. Therefore, the treatment for autism in early days often focused on addressing emotional disturbances that limited parents to interact with children adequately or appropriately. In addition, Bruno Bettelheim's hypothesis of 'refrigerator mother' became popular in the 1950s, which described autism as a result of cold, distanced and insensitive mothers (Joseph, 2018).

Viewing parents as a cause of autism is now considered outdated. The evidence, particularly from the experimentally controlled studies gathered over the years, clearly indicates that parents generally do not suffer from severe psychopathology. Nor are they inadequate or deviant in their ability to provide care for children (Volkmar & Lord, 2008). Keeping in mind this change, it is also important to acknowledge that the misconception about parents in relation to autism is still very much alive in many communities (Joseph, 2018).

Parents' involvement in early intervention

Between the 1970s and 1980s, scientific advances in understanding the aetiology of ASD, as described above, exonerated parents from being wrongly accused of causing their child's autism. Around a similar time, there was a re-conceptualisation of autism as primarily a developmental disorder rather an emotional or psychiatric disorder (Marcus & Schopler, 1989). These changes led to the role of parents to be revised and revalued. Researchers began to acknowledge the significance of parents in children's lives and the importance of parent-child interaction in the early years. In particular, the unique potential of parents to support and expand the therapeutic benefits of early intervention was increasingly recognised (Ruppert et al., 2016). Consequently, a shift was made from excluding parents from the process of intervention to viewing them as a viable agent for delivering necessary intervention for children in the critical years of their early lives.

In the 1960s, Wolf, Risley, and Mees (as cited in Leaf et al., 2017) were the first to report the positive effects of an operant conditioning-based intervention that included a parent-training component. However, Lovaas, who is one of the pioneers of Applied Behavioural Analysis (ABA), was the first researcher to advocate the need for involving parents in early comprehensive behavioural intervention for young children with ASD (Leaf et al., 2017; Shaffer & Minshawi, 2014). In 1973, Lovaas and his colleagues conducted a comprehensive behavioural intervention based on the principles of ABA and observed

positive and meaningful gains in children with ASD (Leaf et al., 2017). More importantly, they found that the children of the parents who were trained in behavioural treatment showed better developmental outcomes post treatment compared to the children of the parents who were not trained. Since then, many researchers have directed their interests in training parents or family members to deliver evidence-based early intervention to their child who is at risk of or being diagnosed with ASD (Wainer & Ingersoll, 2013). Currently, parent-training is acknowledged as an essential component of comprehensive behavioural intervention by two national research guidelines for ASD (National Research Council, 2001; National Standards Report, 2009). The National Standards Report (2015) also identified parent-training as an established intervention that is independent of comprehensive behavioural intervention.

The benefits of parent-training

There are a number of benefits associated with parent training. First, parent-training can provide a long-lasting therapeutic effect. In order to change the developmental trajectory and to maximise the therapeutic effect, the key is to deliver an intervention consistently and intensively over a sustained period of time (McConachie & Diggle, 2006). However, most early intervention programmes delivered by professionals and therapists are time-limited. In fact, one study reported that the average number of hours that early intervention was delivered to children with ASD were far less than what is recommended by national guidelines in the US (Boyd et al., 2010). Training parents to deliver intervention can greatly increase children's access to the necessary intervention throughout the day, resulting in the child receiving more hours of therapy than is able to be offered by an early intervention service (Wainer & Ingersoll, 2013).

Moreover, parents can deliver intervention through daily interactions that occur naturally in an environment where the child is most likely to spend most of his or her early life. This may result in a longer-lasting therapeutic effect than therapist delivered

interventions that occur outside of the natural context (Ruppert et al., 2016). This is particularly true when parents can deliver intervention with high fidelity (Trembath et al., 2019).

Most early intervention services are financially costly and time consuming for many families of children with ASD. The cost of receiving early intensive intervention for two years is estimated to be approximately 45,000 US dollars (Chasson, Harris, & Neely, 2007). The median income of the average US citizen was estimated at 50,233 dollars in 2007, when the research was conducted (Bernstein, 2008). Training parents requires fewer inputs from professional therapist or clinicians than providing therapy directly to children (Shaffer & Minshawi, 2014). Moreover, there is a shortage of human resources in delivering early intervention as it requires individuals with appropriate qualifications (Jacobson & Mulick, 2000). Considering the growing prevalence rate of ASD, it is easy to expect that the shortage is likely to remain and the imbalance between supply and demand will increase. Training parents can compensate for such imbalances without jeopardising children's needs for intervention in their critical years. Furthermore, it is possible that training parents to deliver a basic form of early intervention immediately after receiving a diagnosis of ASD may compensate for the loss of time between the diagnosis and the commencement of an intervention (Siller & Morgan, 2018).

Lastly, parents can directly benefit from the parent training itself. The impact of autism is not limited to an individual child but can also affect his or her family. There are several studies which document parental stresses associated with parenting children with ASD (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Phetrasuwan & Shandor Miles, 2009). Some of the main concerns included difficulty managing children's behaviours and not knowing how to support their child's development, and these are identified as one of the main factors associated with an undermined parental sense of well-being (Phetrasuwan &

Shandor Miles, 2009; Tehee, Honan, & Hevey, 2009). Parent-training is associated with improved parental self-efficacy and reduced levels of parental stress, These appear to contribute to an overall improvement in family functioning (Machalicek et al., 2014; McConachie & Diggle, 2007; Shaffer & Minshawi, 2014).

Parent-training in the field of ASD

Parent-training has a long history beyond the field of ASD. In fact, parent-training was originally developed for parents of typically developing children with challenging behaviours such as aggression or non-compliance (Schaefer & Briesmeister, 1989). Parents are trained in behavioural methods by a therapist and encouraged to apply the learnt techniques or skills with their child. The aim of parent-training is that, by teaching a set of skills and techniques, parents become an active agent in modifying their child's undesirable behaviours while improving the parent-child relationship. The efficacy of parent-training in the field of psychosocial intervention is presumed to be strong when interventions are implemented with fidelity (Garbacz, Brown, Spee, Polo, & Budd, 2014; Sanders, 1999; Webster-Stratton, 1998).

Although parent-training in the field of ASD shares many conceptual similarities with parent-training in the field of psychosocial intervention, it is interesting to note the parent-training for children with ASD entails a variety of labels and modalities (Leaf et al., 2017). First of all, there are many different types of parent-training programmes for children with ASD. These differ in theoretical orientations and practices. The diversity of approaches may be due to the complexity of the nature of autism. Children with ASD tend to present with difficulties in multiple domains of development and thus, require a wide range of supports. This in turn, has spawned a wide range of approaches to intervention and intervention targets. For example, parent-training in the field of ASD may include programmes that help parents to manage disruptive behaviours, support parents to address difficulties with adaptive

behaviours such as sleeping or eating, or teach parents to provide a specific set of skills improve children's developmental domains such as communication or social interaction and etc (Leaf et al., 2017; Shaffer & Minshawi, 2014).

Secondly, there are several terms associated with parent-training in the field of ASD and they are often used interchangeably, causing a great deal of confusion. For instance, Bearss, Burrell, et al. (2015) identified several terms that were related to parent-training for children with ASD. These included parent-education, parent-mediated, parent-implemented, parent-delivered or caregiver implemented intervention. Bearss, Burrell, et al. (2015) proposed two broad categories in an attempt to define and clarify the terms associated with parent-training in the field of ASD; namely parent-support and parent-mediated intervention (PMI).

Parent support. Parent-support refers to parent-training programmes where children are the indirect beneficiary of the intervention as parents receive support for their caregiving and education to increase their knowledge about ASD (Bearss, Burrell, et al., 2015). Parent-support is further categorised into care-coordination and psychoeducation. Care-coordination is a type of support that parents receive to navigate and organise the multiple needs that a child with ASD may require (Bearss, Burrell, et al., 2015). An example of care-coordination is the Comprehensive Medical Care for Autism Spectrum Disorder (AMITEA) developed in Spain, which schedules necessary appointments with clinicians or therapists for families of children with ASD and supports them in attending these appointments. Psychoeducation refers to parent-education, where parents are provided with the latest information about ASD, diagnostic procedures, and appropriate interventions services (Bearss, Burrell, et al., 2015).

Parent Mediated Intervention (PMI). PMI refers to parent-training programmes where children are the "direct beneficiary" of intervention. When using PMI, parents are given specific training by a professional therapist or clinician to learn a set of behavioural

skills or techniques, and expected to act as a primary therapist to deliver intervention for their child (Bearss, Burrell, et al., 2015, p. 4). Currently, PMI is recognised as an empirically validated practice for children with ASD and a growing area of interest in early intervention (Bearss, Burrell, et al., 2015; Leaf et al., 2017; National Standards Report, 2015; Wainer & Ingersoll, 2013).

There are two ways that PMI can be used in early intervention with ASD. First, PMI can be used in conjunction with therapist-delivered intervention in order to increase the therapeutic effect by exposing children to low-intensity intervention at home (Bearss, Burrell, et al., 2015). This form of PMI can contribute to greater maintenance of treatment effects as parents can deliver extra hours of intervention for their children outside of therapist delivered hours (Ruppert et al., 2016). Second, PMI can be used as a stand-alone, low-intensity intervention. This form of PMI provides a viable, cost-effective and efficient alternative to an EIBI (Bearss, Burrell, et al., 2015). Over the last decade, PMI for children with ASD has become increasingly popular, which in turn has resulted in the development of a vast range of PMI programmes (Oono, Honey, & McConachie, 2013; Siller & Morgan, 2018).

Types of PMI. Bearss, Johnson, et al. (2015) categorised the various types of PMI into two main types; PMI for core symptoms (PMI-CS) and PMI for maladaptive behaviours (PMI-MB).

PMI-CS refers to the types of intervention that are primarily focused on training parents to master the specific skill or techniques to work with the core developmental deficits in children with ASD (Bearss, Johnson, et al., 2015). When using PMI-CS, parents are generally taught to apply strategies that promote children's play, imitation, social communication and interaction. Examples of the PMI-CS programmes include the Parent-Implemented Early Start Denver Model (P-ESDM) (Rogers, Dawson, & Vismara, 2012), the parent-mediated Pivotal Response Training (PRT) programme (Amanda Mossman Steiner,

Gengoux, Klin, & Chawarska, 2013), the parent-mediated Joint Attention Symbolic Play Engagement and Regulation (JASPER) intervention (C. Kasari, Gulsrud, Paparella, Hellemann, & Berry, 2015; Connie Kasari, Gulsrud, Wong, Kwon, & Locke, 2010; C. Kasari et al., 2014; Rocha, Schreibman, & Stahmer, 2007), the parent-mediated Joint Attention Mediated Learning (JAML) (Schertz & Odom, 2007), the parent-mediated communication-focused treatment called Preschool Autism Communication Trial (PACT) (Green et al., 2010), and the Hanen's More Than Words (HMTW) programme (Carter et al., 2011).

PMI-MB refers to interventions in which parents are trained to manage the maladaptive and disruptive behaviours of children with ASD (Bearss, Burrell, et al., 2015). Parents are trained in how to deal with tantrums, aggression, self-harm or non-compliance. In some programmes, parents may receive education and training to address the core symptoms of ASD and/or functional communication skill. Examples of the PMI-MB programmes include; Stepping Stones Triple-P (SSTP) for children with autism (Tellegen & Sanders, 2014; Whittingham, Sofronoff, & Sheffield, 2006; Whittingham, Sofronoff, Sheffield, & Sanders, 2009), Incredible Years group-based parenting programme for children with autism (Webster-Stratton, Dababnah, & Olson, 2018), Research Unit for Behavioural Intervention (RUBI) (Aman et al., 2009; Bearss, Johnson, et al., 2015), Child-Directed Intervention Training (CDIT) (Ginn, Clionsky, Eyberg, Warner-Metzger, & Abner, 2017), and Functional Behavioural Skills Training (FBST) (Reitzel et al., 2013).

Effectiveness of PMI. With growing interest in PMI, there have been significant efforts made by a number of agencies and academic researchers to examine its effectiveness (Siller & Morgan, 2018). The Cochrane systematic review and meta-analysis of PMI for children with Autism found that the effect of PMI in producing meaningful changes in children's behaviour was not apparent and the evidence was inconsistent across studies (Oono et al., 2013). This was supported by other academic

reviews (Beaudoin, Sébire, & Couture, 2014; McConachie & Diggle, 2007; Siller & Morgan, 2018). McConachie and Diggle (2007) pointed out that methodological inconsistencies and a lack of randomised control trials were the main reasons limiting the conclusions that were able to be drawn about the effectiveness of PMI. Siller and Morgan (2018) also pointed out that the inconsistent use of outcome measures across studies was problematic. There is also a small body of research to suggest that PMI is less effective than therapist-delivered intervention (Leaf et al., 2017). This may be the result of differences in intensity and method of training across the different PMI programmes (Leaf et al., 2017; McConachie & Diggle, 2007; Oono et al., 2013). Finally, the majority of existing literature reviews regarding the effectiveness of PMI focus on the PMI-CS.

Reviews for the PMI-CS have concluded that there are some benefits associated with PMI, such as improvement in language development or communication skills, but the positive effect of the PMI-CS in improving overall symptoms of ASD may require further research. For example, the two reviews conducted by the Agency for Healthcare Research and Quality reported that, although the studies examining PMI have shown an increase in research quality, the results were limited to improvement in overall symptoms of ASD (Warren et al., 2011; Weitlauf et al., 2014). A recent meta-analysis also concluded that the studies examining the effects of PMI-CS did not produce any significant improvement in children's symptoms of ASD when compared to the control group who received treatment as usual (Nevill, Lecavalier, & Stratis, 2018). However, other reviews reported that PMI-CS was effective in improving language skills or communication skills (Lang, Machalicek, Rispoli, & Regester, 2009; Weitlauf et al., 2014). In addition, Lang et al. (2009) reported, in their systematic review, that parents were able to implement the intervention accurately and consistently after training.

Only one systematic review and meta-analysis was identified that focused on PMI-MB (Postorino et al., 2017). These authors examined the effectiveness of PMI-MB in eight RCT studies and reported a medium effect size (Standardised Difference in means; SMD = -0.59). They concluded that the PMI-MB was efficacious in reducing maladaptive behaviours in children with ASD.

Parental perceptions of PMI programmes. A brief literature search investigating parents' perceptions of PMI found that most studies were focused on examining the effect of the parenting programme on improving children's core symptoms of ASD. Within these studies, parental perceptions of programmes was mainly assessed in terms of parental satisfaction with the programme. The method employed to evaluate parental satisfaction were mostly quantitative methods such as using a questionnaire with a Likert scale (Ruth M Anan, Lori J Warner, Jamie E McGillivary, Ivy M Chong, & Stefani J Hines, 2008; Ilg et al., 2018; Keen, Couzens, Muspratt, & Rodger, 2010; Rocha et al., 2007 ; Smith, Buch, & Gamby, 2000; Wainer & Ingersoll, 2015). A relatively small amount of research used qualitative research methods to explore parents' perceptions and experiences of PMI.

Despite the methodological differences, parents generally reported a high level of satisfaction over the programme and the support received by the staff across studies. For example, two studies explored parental satisfaction using a Likert-scale based parent satisfaction questionnaire within the UCLA parent-training (Smith et al., 2000) and the Group Intensive Family Training (GIFT) (Anan et al., 2008). In both studies, parental satisfaction with the programme and the staff was reported to be high. Parents all reported a positive effect of training on their children's learning and family functioning as well as perceived confidence in parenting their children. However, both studies did not specify what questions they used in their questionnaire. Moreover, less than 70% of parents completed questionnaires in both studies.

Ilg et al. (2018) employed a number of scales to evaluate the social validity of the PMI; a self-developed scale was used to examine parents' perception of the impact of the programme on their children's learning, acceptability of treatment was assessed using the Treatment Evaluation Inventory Short-Form (TEI-SF), consumer satisfaction was assessed using the Therapy Attitude Inventory (TAI) and future use of learnt strategies and likelihood of recommending the programme to others was also assessed. All of the scales employed a five-point Likert scale. In addition to these measures, the French Parent Stress Index (PSI) and Beck's Depression Inventory-short form (BDI-SF) were used to measure the impact of the programme on parental mental health. Results found that 16 out of 18 parents reported a high level of satisfaction with the programme. They stated that the training made a positive impact on their children's learning, and it was well-suited to parents' learning needs which led to the higher likelihood of using the obtained skills in the future. Only two of the parents reported dissatisfaction with the programme and reported that the obtained skills were ineffective in managing their children's challenging behaviours.

Amongst the studies that employed qualitative research methods, a survey using open-ended questions (Dillenburger, Keenan, Gallagher, & McElhinney, 2004), a semi-structured interview (Hodgetts, Savage, & McConnell, 2013; Pickard, Wainer, Bailey, & Ingersoll, 2016) and a focus group (Hodgson et al., 2018) were used to explore parents' perceptions. The results revealed that parents viewed PMI as an effective intervention approach, and they were satisfied with the parent-training. An improved sense of self-confidence and self-efficacy was also noted among parents (Dillenburger et al., 2004; Hodgetts et al., 2013; Hodgson et al., 2018; Pickard et al., 2016). A reduction in the level of stress perceived by parents was reported as well (Hodgetts et al., 2013).

Overall, this brief literature search indicated that parents are highly satisfied with PMI. However, there is an apparent lack of research in this area resulting in an absence of

rich and detailed information pertaining to how parents perceive the value of PMI or what aspects of PMI parents are particularly satisfied with. For instance, in most of the quantitative studies, little attention was given to the parents who reported a relatively low level of satisfaction over the programme. Also, the findings of many quantitative studies were based on a rigid and top-down approach and they were limited to provide a rich and descriptive information of parents' experiences with PMI. Considering the lack of qualitative literature and the related lack of in-depth understanding of parents' experiences of PMI, it is clear that there is a need for a qualitative systematic review on this topic. A qualitative systematic review can not only reveal the available research regarding parents' perceptions of PMI using a rigorous and systematic search method but would also synthesise the findings of individual studies in a holistic and meaningful way.

Parent-implemented Early Start Denver Model (P-ESDM)

A brief overview of ESDM

The Early Start Denver Model (ESDM) is a comprehensive developmental and behavioural intensive early intervention for young children with ASD (Kodak & Carroll, 2017; Rogers & Dawson, 2010). As a comprehensive intervention model, the ESDM targets multiple developmental domains including social, language and cognitive development, play skills, and adaptive functioning. According to Waddington, van der Meer, and Sigafoos (2016), the ESDM programme can be classified as a Naturalistic Developmental Behavioural Intervention (NBDI). The term NDBI refers to a type of EIBI that integrates ABA techniques within a naturalistic, child-led teaching approach. ESDM is unique in two ways. First, it is specifically designed to address the developmental needs of young children with ASD; and second, it is the only model that has been recognised and validated as an effective early intervention approach for children under two years of age (Kodak & Carroll, 2017).

Sally Rogers, a developmental psychologist, and Geraldine Dawson, a child clinical psychologist, are the two main contributors to the development of the ESDM. According to Rogers and Dawson (2010), multiple approaches were incorporated into the construction of this model. These included the original Denver Model and Pivotal Response Training (PRT).

The original Denver Model, which provided the foundation for the ESDM, is a comprehensive developmental, relationship and play-based intervention. Hence, the ESDM conceptualises autism from a developmental framework and values the relationship between child and adult in the early development of language and communication (Rogers, 2016). The focus of ESDM is, therefore, to facilitate the growth of a positive parent-child relationship. Another focus of ESDM is to create a wide variety of "communicative opportunities" between parents and child that are naturalistic and spontaneous in nature to evoke children's "communicative behaviours" (Rogers & Dawson, 2010, p. 18). The curriculum of ESDM is designed based on the typical development of children between 9 to 48 months, and the intervention is delivered in developmentally appropriate sequences (Rogers, 2016).

PRT is a child-led, naturalistic intervention for children with ASD that is based on the principles of ABA (Charlop, Lang, & Rispoli, 2018). Rogers and Dawson (2010) stated that, although PRT is based on the principles of ABA, it is distinctive from Discrete-Trial Training (DTT), as it aims to "optimize children's motivation" by following children's interests (p. 17). The principles of PRT included in ESDM are: (1) positive reinforcement of children's communicative attempts, (2) interspersal of previously learnt tasks and newly targeted skills, (3) direct response-reinforcer relationship, (4) turn-taking, (5) using clear and appropriate prompts and (6) encouraging and following children's choices. The inclusion of the PRT strategies distinguishes the ESDM from the original Denver Model.

The conceptual basis for ESDM is the model of interpersonal development in autism and the social motivation hypothesis of autism (Rogers & Dawson, 2010). Rogers and

Pennington (1991) developed the model of interpersonal development in autism. In this model, they hypothesised that children with ASD have a deficit in their capacity to imitate, which has an enduring effect on the early development of social milestones. Their view was that imitation is the very first means for infants to learn and share their feelings and needs with their caregivers and vice versa. With a deficit in this area, an infant may have difficulty developing an ability to understand and interpret other's intentions. Since understanding other's intentions is thought to be of foremost importance for human learning, the ESDM places particular value on developing imitation skills in young children with ASD (Rogers, 2016). The social motivation hypothesis of autism refers to the notion that children with ASD may have impaired social motivation. Techniques such as 'sensory social-routines' or 'following children's interests' are designed to compensate for this inherent difficulty of children with ASD and enhance their motivation to engage in social interaction (Rogers & Dawson, 2010).

Parent training in ESDM

Parent-implemented ESDM (P-ESDM) is a manualised PMI, using a dedicated manual, *An early start for your child with autism* (Rogers, Dawson, et al., 2012). This manual covers ten core elements of ESDM; (1) capturing children's attention, (2) sensory social-routines, (3) dyadic interaction between parent and child, (4) non-verbal communication, (5) imitation, (6) antecedent-behaviour-consequences (ABC), (7) joint attention, (8) functional play, (9) symbolic play and (10) expressive communication. Through parent-training for P-ESDM, parents gain mastery of the techniques and strategies relevant to these ten elements from a trained therapist in order to deliver P-ESDM at home for their child.

Within the P-ESDM programme, parents are provided with a one-hour to 90-minute training sessions and the format of these sessions includes; (1) 'progress report' where the coach and the parents discuss and evaluate the techniques learnt in the previous week, (2)

'warm-up activity' where parents engage in a play activity of their choice with their child, (3) 'reflection' where the parents and the coach reflected on the warm-up activity, (4) 'therapist modelling' where the therapist introduces a new technique and model it to parents, (5) 'parent practice 1' where the parents practised the introduced techniques while the therapist provide additional coaching as needed, (6) 'parent practice 2' where the parents practised the newly learnt techniques in a different activity to facilitate their generalisation of the technique at home, (7) 'feedback' where parents and therapist discuss any questions that parents may have and plan for following week (Rogers, Dawson, et al., 2012).

The training is typically delivered for 12 weeks. It begins when the therapist has identified parental goals and conducted an assessment of the child's developmental level in relation to the ESDM curriculum. The therapist then reviews the results of the child's assessment and creates learning objectives in collaboration with the parents. The identified learning objectives guide the process of how the therapist delivers training to meet the needs of the parents and their child. The parent-training is based on the partnership model for coaching, suggested by Hanft, Rush and Shelden (as cited in Talbott, Estes, Zierhut, Dawson, & Rogers, 2016), where the therapist acknowledges the values, beliefs and preferences of parents and their knowledge and strengths and incorporates these into the process of training.

Effectiveness of P-ESDM

Eleven studies were identified that have examined the effectiveness of P-ESDM (Estes et al., 2014; Rogers, Estes, et al., 2012; Rogers et al., 2019; Rogers et al., 2014; Vismara, Colombi, & Rogers, 2009; Vismara, McCormick, Young, Nadhan, & Monlux, 2013; Vismara et al., 2018; Vismara & Rogers, 2008; Vismara, Young, & Rogers, 2012; Waddington, van der Meer, & Sigafoos, 2019; Zhou et al., 2018). Nine of these studies were conducted in the US, while one was conducted in China (Zhou et al., 2018), and the other was in New Zealand (Waddington, 2018). Interestingly, only one study (Waddington et al.,

2019) had no involvement from Rogers, Vismara or Dawson (the developers of the P-ESDM manual), but the rest of the studies included at least one of them as an author of the research.

Four studies employed a single-subject design to examine the effectiveness of P-ESDM delivered in person (Vismara et al., 2009; Vismara & Rogers, 2008; Waddington, 2018). Two of the four studies (Vismara et al., 2009; Vismara & Rogers, 2008) reported a positive improvement in children's social-communicative behaviours. Waddington (2018) also reported that four out of five children showed improvement in at least one area of child outcome variables such as imitation, engagement or verbal utterances. All three studies reported that the majority of parents achieved a high level of fidelity and suggested that parents can learn to implement the ESDM strategies with acceptable integrity.

Four studies compared face-to-face group delivered P-ESDM training with a control group who received another type of community intervention (Estes et al., 2014; Rogers, Estes, et al., 2012; Zhou et al., 2018) or no intervention (Rogers et al., 2014). In comparison to treatment as usual or no treatment, the P-ESDM group showed a positive improvement in children's overall developmental outcomes, especially in relation to expressive and receptive language skills (Rogers et al., 2014; Zhou et al., 2018). Rogers et al. (2014) also suggested potential benefits of P-ESDM on children under one-year-old who are at risk of ASD. However, Rogers, Estes, et al. (2012) reported that there was no significant difference between the P-ESDM group and the treatment as usual group, in terms of parent fidelity, children's outcomes, and parent-child interaction. It is important to acknowledge that the treatment as usual group received nearly twice the hours of intervention than the P-ESDM group in this study. Also, Rogers, Estes, et al. (2012) employed a Randomised Controlled Trial (RCT) design, while Rogers et al. (2014) and Zhou et al. (2018) employed a non-randomised controlled trial design. In terms of parents' use of ESDM techniques, all three

studies, except Zhou et al. (2018), investigated and reported that parents mastered and maintained the techniques learnt through training.

Rogers et al. (2019) conducted an RCT to compare the effectiveness of the basic model of parent-training for P-ESDM and an intensive model of parent-training for P-ESDM which consisted of more hours and materials, and the use of multiple modalities and motivational interview techniques. Parents from the intensive training model demonstrated a significant improvement in their skills and fidelity when compared to those who received the basic training model. Interestingly, there were no group differences in relation to child outcome variables, even though children in both groups demonstrated positive gains in their social and communication skills. This suggested that the degree of parental mastery and fidelity of implementation of ESDM techniques does not necessarily translate to improvement in the child.

Three studies investigated the effectiveness of a telehealth approach to P-ESDM, which was designed to deliver parent-training via an online medium (Vismara et al., 2013; Vismara et al., 2018; Vismara et al., 2012). All of them reported that a telehealth approach to P-ESDM was a feasible and acceptable form of intervention to parents. They also reported that a telehealth approach to P-ESDM was positively associated with improvement in parents' ability to use the ESDM techniques and improvement in children's social and communicative skills. In particular, Vismara et al. (2018) conducted an RCT and reported that P-ESDM produced better parental fidelity and satisfaction than the community group who had access to online resources that were unrelated to ESDM. However, there were no group differences in terms of the outcomes relating to children's social and communicative skills.

Overall, the P-ESDM programme appeared to have a positive impact on increasing parents' use of the ESDM techniques and strategies regardless of its format (parent-training

in person or via online). However, the impact on children's developmental outcomes appears to vary greatly across studies. Moreover, there were only two studies which used an RCT to compare its effectiveness to another type of intervention or no-treatment. One of them had major limitations to its sample, as the control group received more intervention hours than the P-ESDM group. In addition, the majority of studies were conducted by or involved the developer of the P-ESDM directly. This suggests that there is a need for more rigour in evaluating the effectiveness of P-ESDM and a need for more independent studies. It was interesting to note that the characteristics of the sample were largely based on a Caucasian population. Most of the parents showed a relatively high level of education, and they were highly motivated to learn. This homogeneity of the sample may also limit the generalisability of the findings.

Parents' perception of P-ESDM

Six of the eleven studies (Rogers et al., 2019; Rogers et al., 2014; Vismara et al., 2013; Vismara et al., 2018; Vismara et al., 2012; Zhou et al., 2018) examined parental satisfaction, or parent evaluated social validity of the P-ESDM programme.

Only Vismara et al. (2012) used an open-ended questionnaire to explore parents' perception regarding the feasibility and acceptability of the telehealth based ESDM parent-training. Eight out of nine parents, who expressed initial concerns regarding the effectiveness of a telehealth approach, reported that it was as informative and valuable as the conventional face-to-face parent training approach, while some parents suggested the need to combine live video-conference sessions with video examples to aid the effectiveness of the sessions. Frustration regarding technical problems was also noted.

Five of the six studies employed quantitative measures to explore parents' satisfaction and perception of the utility, feasibility and acceptability of P-ESDM (Rogers et al., 2019; Rogers et al., 2014; Vismara et al., 2013; Vismara et al., 2018; Zhou et al., 2018). These

measures included the Intervention Evaluation Form for Parents (IEF-P) (Rogers et al., 2019), and researcher developed parent satisfaction rating scales (Rogers et al., 2014; Vismara et al., 2013; Vismara et al., 2018; Zhou et al., 2018). The results of the five studies indicated that most of the parents were highly satisfied with parent-training based on the ESDM. There were no differences between the conventional face-to-face approach to parent-training and the telehealth approach. They all reported a satisfactory level of support was recieved by the therapist or the staff and indicated that the contents of the training were adequate. Most of the parents reported a high level of confidence in implementing the ESDM techniques.

An in-depth qualitative inquiry to explore parents' perceptions and experience with ESDM based parent-training was found in a recent doctoral disertation by (Waddington, 2018). As a part of her doctoral dissertation, Waddington (2018) provided parent-training based on ESDM to five parents of a child with a diagnosis of ASD. She conducted a semi-structured open-ended interview with parents after the training, and analysed the interview data using a deductive thematic analysis informed by the theories of social validity. Four major themes were discovered and named as 'effect on child outcomes', 'model of intervention', 'parent training procedures' and 'relationship with the trainer'. They were further divided into two subthemes ('strengths' and 'challenges'), except 'parent training procedures' which included 'improvements' as an extra subtheme.

Waddington (2018) reported that, in general, parents percieved the ESDM technqiues taught in the training to be acceptable. A majority of the parents reported that their relationship with the trainer was important and noted that the personal charateristics of the trainer made a positive impact on their relationship. It was also reported that the parents valued a positive relationship between the trainer and their child. In terms of the training procedures, most parents reported a desire for longer hours and additional training sessions.

The author hypothesised that 12 weeks of parent-training might have been inadequate for parents to feel confident in implementing all of the ESDM strategies taught in the training. The training procedures that each parent percieved to be most helpful were varied and differed from each other. The author highlighted the individual differences in preferred method for learning and suggested a need for further investigation regarding the benefit of individualising the training procudure.

Overall, the existing research suggests a high level of parental satisfaction relating to P-ESDM. However, most of the results have been obtained from quantitative measures. Only two studies employed a qualitative method for exploring parents' perceptions regarding P-ESDM (Vismara et al., 2012; Waddington, 2018) and one of these did not use a qualitative analysis. Vismara et al. (2012) employed a survey with a list of open-ended questionnaires but provided only a brief explanation of the survey results, and it was not anlaysed in a qualitative manner. Consequently, the perceived benefits or limitations that the parents experienced in relation to P-ESDM were less likely to be captured in detail. From this, it is clear that there is a lack qualitative information regarding how parents perceive and experience P-ESDM. Exploring parents perceptions and experiences using a qualitative research method can bring out the effects of PMI from the user-perspectives and uncover the underlying mechnism that enable parents to achieve the therapeutic success through PMI.

CHAPTER 3

RATIONALE AND METHODOGY

In the field of early intervention for children with ASD there has been a growing recognition and acknowledgement that parents are an essential pillar of children's well-being and development. More specifically, parents are increasingly seen as having the capacity to deliver intervention for their child with ASD. As a result, there has been a rapid increase in the volume of research concerned with training parents in evidence-based early intervention techniques for their child with ASD, namely PMI. In the literature review above, PMI is defined as a type of parent-training programme that is systematically designed to teach parents to deliver evidence-based intervention techniques to their child with ASD. Research indicates that parents are capable of mastering and delivering intervention techniques with fidelity (Lang et al., 2009; Wainer & Ingersoll, 2013). PMI is associated with positive developmental outcomes in children with ASD and improvement in the psychological well-being of parents, as well as improved parent-child interaction (Leaf et al., 2017; Machalicek et al., 2014; McConachie & Diggle, 2007; Oono et al., 2013). Furthermore, it is reported that parents have rated PMI as the most effective and efficacious intervention for making meaningful change in their child's growth when compared to 19 other intervention services available for children with ASD (Hume, Bellini, & Pratt, 2005).

However, little attention has been paid to exploring parents' perceptions or their experiences of PMI. As described in Chapter 2, the majority of research on PMI has focused on investigating the effectiveness of interventions for child outcomes. Furthermore, the impact of the intervention on parents is considered as secondary and the parents' outcomes are often explored using brief surveys or questionnaires (Pickard et al., 2016; Stahmer et al., 2017). Parents' perceptions of PMI are examined in a similar, cursory manner with parents asked to complete a short survey using a Likert scale to indicate their satisfaction with the

intervention (Pickard et al., 2016). Although the use of a Likert scale enables the researchers to present a general understanding of the parents' level of satisfaction with the intervention, it does not capture an in-depth understanding of how the parents perceived or experienced PMI. As a result, there is a significant lack of knowledge and understanding in what factors promote and/or limit parents' engagement in PMI or what benefits they perceive from PMI.

According to Rogers (2003), the perceptions of the participating members of the intervention, on aspects such as the feasibility or acceptability of the intervention, play a significant role in determining how well the members would implement, and how sustainable the intervention would be, in a given setting. Considering the unique characteristics of PMI, which place the parents at the centre of the process of delivering early intervention, the lack of understanding of parents' perceptions of PMI is likely to hinder the effective adaptation and implementation of the intervention.

Drawing from the identified gaps in the literature and the clinical significance of understanding parents' perspectives of PMI, it is clear that there is a need for further investigation within this area of inquiry. The primary objective of this thesis is to explore parents' perceptions of the parent-training component of PMI. To be more specific, this thesis aims firstly to understand parents' perceptions and their experiences of participating in parent-training, and secondly to evaluate the outcomes of PMI from the perspective of parents.

The present thesis is composed of two studies. In the first study, a systematic review of qualitative research is conducted to explore what is known about parents' perceptions and attitudes towards PMI. This review has three main objectives: first, to evaluate the quality of the extant research, secondly to identify the elements of parent-training that contributed positively or negatively to parents' perceptions of PMI; and thirdly, to examine how parents perceived the benefits or outcomes of PMI.

In the second study, a qualitative analysis was performed on interview transcripts of parents who received ESDM based parent-training, followed by low intensity ESDM direct therapy delivered by a therapist to their child. The main objective of this study was to understand not only how parents perceived the ESDM based parent-training, but also how they compared the parent-training to the low-intensity direct therapy. To do so, the analysis was performed separately on each topic; with interviews regarding parent-training, direct-therapy and a comparison between parent-training and direct-therapy.

Methodology

Research design

Study 1: Qualitative systematic review and synthesis. In reviewing the research regarding parents' perception of PMI, I did not intend to present a description of statistical findings or test a set of hypotheses. Instead, I aimed to bring together findings from the existing research to develop an insight into parents' experiences and perceptions of PMI, and to provide a meaningful interpretation of the findings discovered by the primary researchers. For this purpose, a systematic review and synthesis of qualitative literature were deemed to be most suitable.

Conducting a systematic review and synthesis of qualitative research has a number of potential benefits. Firstly, to the best of my knowledge, this is the first study attempting to conduct a systematic review and synthesis of qualitative research regarding parents' perception of PMI. Secondly, reviewing and synthesising qualitative literature using a systematic review methodology provides a rigorous and comprehensive overview of the research findings. A systematic review methodology is a powerful means to identify, evaluate and synthesise published literature using a standardised, systematic, rigorous and transparent process (Dixon-Woods et al., 2006; Popay, Rogers, & Williams, 1998). It is also thought to provide reliable and replicable evidence. Furthermore, attempting to synthesise qualitative

evidence regarding parents' perceptions may inform the future use of PMI with children with ASD. As stated by Dixon-Woods and Fitzpatrick (2001), "rigid insistence on controlled trials as the sole source of evidence on effectiveness that characterised the beginnings of the evidence-based healthcare movement is fading" (p. 765). The decision-making process of healthcare practitioners, policymakers and clients cannot be solely guided by the effectiveness of interventions claimed from tightly controlled experimental studies (Evans & Pearson, 2001; Oakley, 2002; Popay et al., 1998). The perspectives of the people and their needs in relation to the acceptability and appropriateness of the intervention must be included (Popay et al., 1998; Thomas & Harden, 2008).

Lastly, summarising and interpreting the existing evidence regarding parents' perception of PMI may provide some insights into parents' wants and needs and may contribute toward bringing parents perspectives into the decision-making process.

Study 2: A qualitative analysis of parents' perceptions. A separate qualitative analysis was conducted regarding parents' experiences and perceptions of participating in ESDM-based parent-training and low-intensity ESDM direct-therapy. This was considered to be beneficial in providing further insight into parents' wants and needs. In this study, secondary data was used. The interview regarding parents' perception of ESDM-based parent-training and low-intensity therapy was conducted by Dr Hannah Waddington and her research team at Victoria University of Wellington and provided to me for the purpose of analysis.

The proposed analysis of parents' perception of ESDM based parent-training is not novel. A similar study was conducted by Waddington (2018) in her doctoral thesis. Waddington (2018) provided ESDM-based parent-training to parents of five children with ASD and performed a qualitative analysis of the interviews with the parents regarding their experiences of the training. The interviews were conducted independently, and the data was

analysed by Waddington (2018), who designed and provided the training as the primary researcher.

However, this study is distinctive to the work of Waddington (2018) in several aspects. Firstly, the analysis is conducted independently and in a standalone manner to explore parents' perceptions. Secondly, unlike the analysis of Waddington (2018) which was informed by the notion of social validity, an inductive approach to analysis was adapted to further uncover the insights of the parents by allowing a consideration of their spontaneous comments. It was adopted also to further distance myself from possible preconceptions inherent in the work of Waddington (2018) and embodied in the content of Waddington's interview questions. Lastly, this study attempts to provide a comparison of parents' satisfaction and preferences regarding both parent-training and direct therapy. It is to understand which form of intervention may align better with parents' needs. This is unique to this study in that it has never been explored before. Overall, it is hoped that the information gathered from parents and the findings from the analysis may be of some value in providing direction to the future programme planning and delivery the ESDM for families of children with ASD.

Research questions

Study 1: A systematic review and synthesis of the qualitative literature. The systematic review and synthesis of the existing qualitative research require a clearly defined research question, and it "must be broad enough to be of interest but small enough to be manageable" (Evans & Pearson, 2001, p. 112). Following on this guideline and reflecting on the primary objective of the identified studies, a set of research questions were developed and presented below:

1. What are perceived facilitators and barriers to parents' engagement in PMI?
2. What are the outcomes or benefits of PMI perceived by parents?

Study 2: A qualitative analysis of parents' perceptions. In order to gain a better understanding of how parents perceive ESDM-based parent-training and low-intensity direct therapy, an inductive analysis approach using a loose set of questions was used, rather than a strict hypothesis. In keeping with this, an iterative and flexible approach was adopted in the development of the research questions. According to Agee (2009), "understanding the unfolding lives and perspectives of others" requires more than just placing a "satisfactory" set of questions in the beginning but a "reflective and interrogative" process of developing and refining the research questions throughout the entire research process (p. 432).

In this respect, a set of broadly defined goals was developed first, and used as a guide to the analysis process. They were re-visited and refined through the entire analysis process. The goals included:

1. To understand parents' experience of participating in the ESDM-based parent-training.
2. To understand how parents perceived the ESDM direct therapy provided by a trained therapist to their child.
3. To explore how parents compared the parent-training to the direct ESDM therapy that their child received from a trained therapist.

Positioning myself as the researcher

The ultimate goal of qualitative research is to explore and understand human behaviours and experiences through examining the perceived reality of an individual or a group of individuals (Elliott, Fischer, & Rennie, 1999). Therefore, data gathered in qualitative research is based upon the constructed and self-perceived reality of people who are embedded in a given culture and social system. The analysis of the data depends on the subjective interpretation of researchers who are again embedded in the same or different cultural and social system. From this, it is inconceivable to assume that researchers in

qualitative research can remain objective or be completely detached from their own subjectivities. It is also impossible to believe that the researcher is completely and totally free from being influenced by the process of obtaining, analysing and making sense of the data gathered during the research process (Dowling, 2006). Rather than committing to achieving the seemingly impossible task of establishing objectivity in qualitative research, Elliott et al. (1999, p.216) stated that "a self-reflective attempt" made by researchers "to 'basket' existing theory and their own values allows them to understand and represent their informant's experiences and actions more adequately than would be otherwise possible." In this respect, I seek to make myself visible by sharing my own values, perspectives and experiences that are relevant to the analysis that I have conducted for this thesis.

I have a professional background in early childhood education, and I am academically interested in early intervention for young children with ASD. Through my professional experience, I have experienced and became frustrated with how difficult it was for parents and teachers to access appropriate support or resources when there is a concern regarding young children's development. Based on my own interests in early intervention and Autism Spectrum Disorder (ASD), I have searched for ways to support families of children with early developmental concerns. The search led me to learn about an intervention approach for young children with ASD, called the Early Start Denver Model (ESDM), and the work of Dr Hannah Waddington at the Victory University of Wellington. Upon contacting Dr Waddington in late 2018, she provided me with an opportunity to analyse the interview data gathered through one of her experimental research studies looking at the effectiveness and feasibility of the ESDM based parent-training and the low-intensity ESDM direct therapy. Through this journey, I became very interested in the ESDM and the concept of training parents to become a co-therapist for children with ASD. I believe in the potential benefits of ESDM and parent-training for children with ASD. Therefore, I acknowledge here that my

personal and professional interests and passion led me to make a personal connection to this study.

Personally, I emigrated to New Zealand from South Korea as a young adult and English is my second language. Therefore, my social and cultural positioning may differ from those of the participants from Study Two. According to Cortazzi and Jin (2006), the researcher who shares a similar cultural identity and contextual understanding to the participants has a better chance to understand and translate the intended meaning of the participants through analysis. Given the unique, complex and highly subjective nature of constructing personal and cultural identity, however, I believe no one could truly and accurately translate another person's reality and perspectives, regardless of how close or similar the researcher might be with the participants. Nevertheless, to ensure the potential risk of misinterpreting the intended meaning expressed by participants, the extraction of the segmenting contents of the transcript were extensively reviewed with my supervisor, who shared a more similar social and cultural background to the participants, before proceeding to coding.

As a researcher, I refer to myself as an independent analyst. In relation to Study Two, I did not engage in the process of preparing, conducting and completing the interview carried out by Dr Waddington's research team. In order to ensure the independent and rigorous assessment and analysis of the interview data, it was agreed that the results of the quantitative data analysed by the experimental research team and the result of qualitative data analyse by me were not to be shared during the analysis process. The identities of the participants were completely unknown me, as the verbatim transcripts of the interview were prepared by the experimental research team and provided to me with pseudonyms. From this, it is possible to assume that I am free of substantial conflicts of interests.

CHAPTER 4

STUDY 1:

Qualitative systematic review and synthesis of parents' perceptions of parent-mediated intervention for children with ASD

This chapter presents a systematic review and synthesis of the qualitative literature relating to parents' perceptions of PMI, where parents were trained to deliver evidence-based intervention techniques to their child with ASD. The main objective of this review and synthesis is to develop a greater understanding of how parents experience and perceive PMI by identifying factors that facilitate or act as barriers to parents' engagement in parent-training as well as parents' perceived outcomes of PMI.

Methods

This systematic review was undertaken in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement. The PRISMA statement is a well-established guideline used for reporting systematic reviews and meta-analyses of health research.

Systematic search and screening

Search procedure. An internet search of the electronic databases Psych Info, MEDLINE, PubMed and Scopus. Initially, the following search terms were entered: (a) 'autism', 'asd', 'autism spectrum disorder' and "autistic", (b) 'therapy', 'treatment' and 'intervention', (c) 'parent implemented', 'parent delivered', 'parent mediated', 'parent coach*' and 'parent train*', and (d) 'attitude*', 'perception*', 'opinion*', 'thought*', 'feeling*', 'belief*', and 'experience*'. In each group, the key terms were combined using the OR operator, and the groups were combined using the AND operator. The search was limited to literature published in English and no restriction was placed on the date of publication. The reference lists of identified articles and relevant literature reviews were also

examined to identify additional studies that may not have appeared in the initial electronic search. Finally, a search of Google Scholar was conducted using the aforementioned search terms.

Inclusion and exclusion criteria. To be included in this review, each study met the following inclusion criteria: (a) the studies employed quantitative methods to examine parental perspectives or satisfaction with PMI; (b) at least one parent must have participated in a parent training programme where a therapist or clinician provided on-going training and education to teach them how to implement ASD-specific intervention strategies or skills in the home environment; (c) the parents must have received on-going supervision and support from the therapist or clinician to implement the learnt strategies or skills; (d) the training occurred across more than one session; (e) all children had a diagnosis of ASD or were identified as being at risk of ASD; and (f) the full-text of the article was available. Articles that did not meet the above inclusion criteria were excluded. In addition, literature reviews, unpublished dissertations, commentaries or editorial papers were excluded.

Search results. An initial literature search identified 358 studies. Of the 358 studies, 134 were found to be duplicates and excluded. The remaining 224 studies were reduced to 66, following a title and abstract review. A full text evaluation was conducted with the 66 studies. Of the 66 studies, 51 studies were excluded as they did not meet the inclusion criteria. Of the 51 studies, 25 studies did not explore parents' perceptions or experiences, 14 studies failed to meet the inclusion criteria for the parent-training programme, five studies included children without a identified risk or a diagnosis of ASD, five studies had inadequate qualitative data to be included in the review, 2 studies had full-text unavailable. A total of 15 studies were identified that meet all of the inclusion criteria. A summary of the systematic searching process is provided in Figure 3.

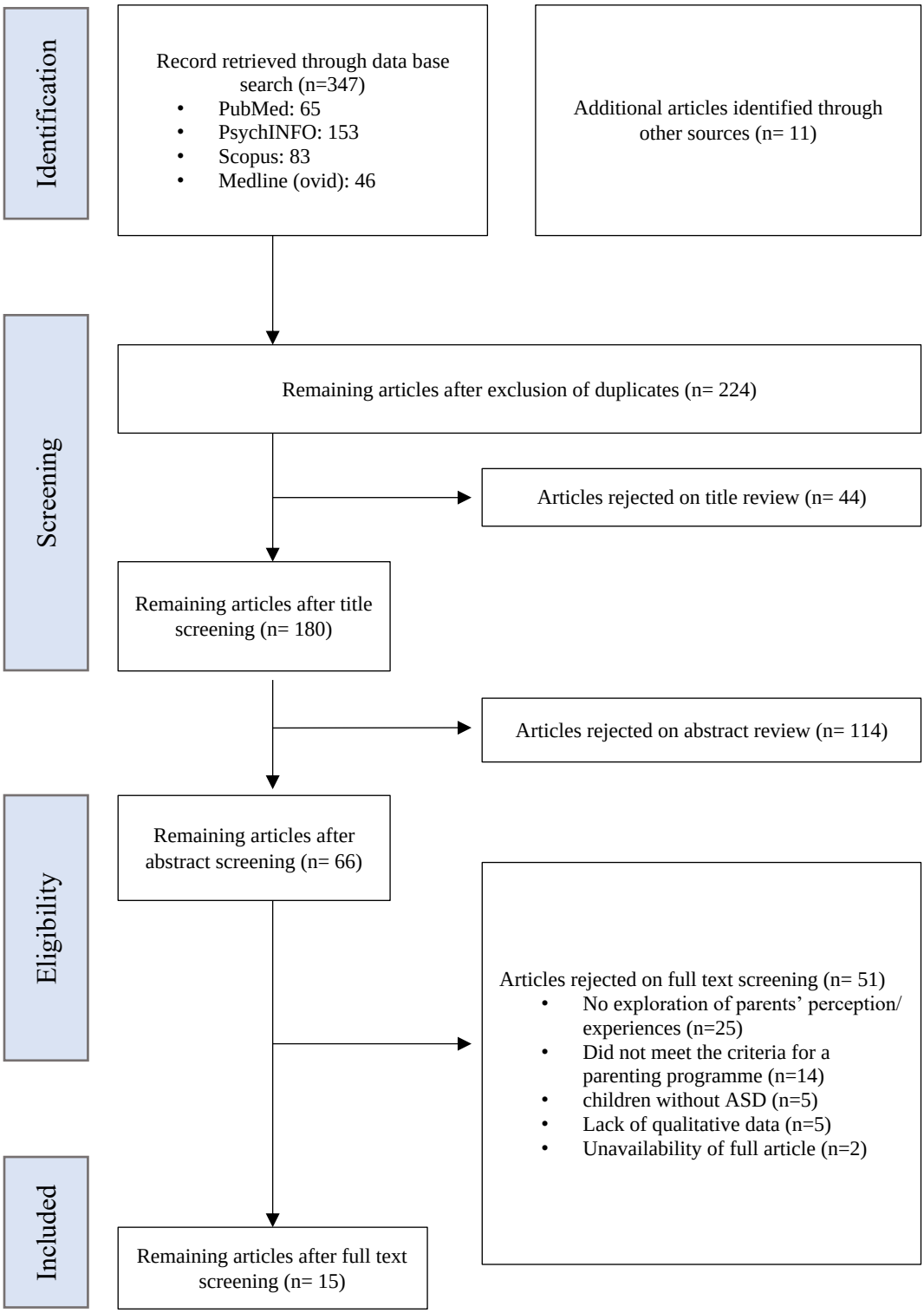

Figure 4.1 *PRISMA flow diagram demonstrating the results of the systematic literature search*

Appraisal of methodological rigour. The quality of the identified studies was appraised by the primary author of this review using the Mixed Method Appraisal Tool (MMAT; Hong, Pluye, et al., 2018). The MMAT is designed for systematic reviews that include qualitative, quantitative, and mixed method studies (Hong, Fàbregues, et al., 2018). As the studies included in this review used qualitative and mixed method research designs, the MMAT was considered the most appropriate tool to evaluate study rigour, rather than applying two quality appraisal tools; one for qualitative studies and another for mixed method studies. The MMAT is reported to have sufficient efficiency and reliability (Pace et al., 2012).

The MMAT has five categories each relating to a specific type of research design (1) qualitative, (2) quantitative randomised controlled trial, (3) quantitative non-randomised controlled trial, (4) quantitative descriptive, and (5) mixed method studies. Each category consists of five quality criteria. In additions, the MMAT has two screening questions applicable to all research designs. The methodological quality criteria of the MMAT are presented in Table 4.1.

Table 4.1

Quality rating of the Mixed Method Appraisal Tool (MMAT)

Study Design	Methodological quality criteria
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question? 1.2. Are the qualitative data collection methods adequate to address the research question? 1.3. Are the findings adequately derived from the data? 1.4. Is the interpretation of results sufficiently substantiated by data? 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
2. Quantitative randomised controlled trials	2.1. Is randomisation appropriately performed? 2.2. Are the groups comparable at baseline? 2.3. Are there complete outcome data? 2.4. Are outcome assessors blinded to the intervention provided? 2.5 Did the participants adhere to the assigned intervention?
3. Quantitative non-randomised	3.1. Are the participants representative of the target population? 3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? 3.3. Are there complete outcome data? 3.4. Are the confounders accounted for in the design and analysis?

	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question? 4.2. Is the sample representative of the target population? 4.3. Are the measurements appropriate? 4.4. Is the risk of nonresponse bias low? 4.5. Is the statistical analysis appropriate to answer the research question?
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed-methods design to address the research question? 5.2. Are the different components of the study effectively integrated to answer the research question? 5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? 5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? 5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?

Using the MMAT involves three steps. These are (1) posing two screening questions; 'S1: *are there clear research questions*?' and 'S2: *Do the collected data allow to address the research questions?'*, (2) determining the research category involved based on the five categories described above; and (3) applying the appropriate quality criteria and rating each criterion with 'Y', 'N' or 'CT'. 'Y' indicates that the criterion is met, 'N' that criterion is unmet, and 'CT' which refers to 'can't tell' which indicates that the study lacks the appropriate information to assign 'Y' or 'N'.

In the first step of the appraisal, MMAT recommends that reviewers use the two screening questions to determine whether a further appraisal of the identified studies would be achievable and appropriate (Hong, Fàbregues, et al., 2018). If a study satisfies both of the screening questions, it is deemed appropriate for further appraisal. However, if a study fails to meet any one of the screening questions, it is recommended that it is excluded from further appraisal as it is not an empirical study.

Due to a lack of clarity regarding the second screening question (S2: *Do the collected data allow to address (sic) the research questions?),* the decision was made to include the seven appraisal prompts derived from the checklist of Critical Apprasisal Skills Programme

(2019). The included prompts are presented in the Table 4.2. If a study met less than three out of the seven prompts, it was given a rating of 'N' in relation to the second screening question.

Table 4.2

Seven prompts added to S2

1. If the setting for the data collection was justified
2. If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
3. If the researcher has justified the methods chosen
4. If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
5. If methods were modified during the study. If so, has the researcher explained how and why
6. If the form of data is clear (e.g. tape recordings, video material, notes etc.)
7. If the researcher has discussed saturation of data

Of the 15 studies identified through the search, three were identified as unclear regarding whether they satisfy both screening questions. After a discussion with my supervisors, two studies (Brezis et al., 2015; Cutress & Muncer, 2014) were appraised while one study (Dillenburger et al., 2004) was excluded. Table 4.3 illustrates the result of the application of the two screening questions to the 15 studies. The result of the seven prompts used for S2 is provided in Table A.2 in Appendix A.

Table 4.3

Result of the application of the screening questions

	Brezis, et al. (2015)	Chlebowski, et al. (2018)*	Donaldson, et al. (2011)	Foster, et al. (2013)	Freuler, et al. (2014)	Hodgson, et al. (2018)	Patterson & Smith (2011)*	Wallisch, et al. (2019)	An (2017)	Cutress& Muncer (2014)	Dillenburger, et al.(2004)	Hodgetts, et al. (2013)	Pickard,et al. (2016)	Rivard, et al. (2017)	Stahmer, et al. (2017)
S1	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
S2	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y

Once the screening questions were completed, exclusion of any studies based on the result of further appraisal is discouraged. Of the 14 studies included for the further appraisal, eight studies were identified as qualitative studies, and assessed based on the five quality criteria for qualitative study category of the MMAT. The third quality criterion for qualitative studies (1.3: *Are the findings adequately derived from the data?*) were modified to include

the seven appraisal prompts derived from the checklist of Critical Apprasisal Skills Programme (2019), which is described in Table 4.4. If a study met more than three out of seven prompts, it was given 'Y' to the criterion 1.3. The outcomes of the application of the seven prompts on the 14 studies are provided in Table A.3 in Appendix A.

Table 4.4

Seven prompts added for the criterion 1.3

1. Is there an in-depth description of the analysis process
2. Is thematic analysis used. If so, is it clear how the categories/themes were derived from the data
3 Does the researcher explain how the data presented were selected from the original sample to demonstrate the analysis process
4. Were sufficient data presented to support the findings
5. Were methods modified during the study. If so, has the researcher explained how and why
6. To what extent were contradictory data taken into account
7. Has the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

The remaining six studies were identified as mixed-method studies. They were assessed based on the 15 quality criteria for the mixed method study category. Five criteria are for the qualitative component, five criteria are for the quantitative descriptive component, and five criteria are for the mixed method component of the study (see Table 4.1 for details).

Data extraction and synthesis of results

Data extraction. Each study was summarised according to; (1) geological location of study, (2) methodology, (3) participant details (number of participating parents, their gender and the age of their children), (4) data collection method, (5) data analysis method, and (6) type of parent-training programme and its delivery method. A descriptive table was created based on this information (see Table 4.5).

For the data synthesis, the section labelled as 'results' or 'findings' in all of the included studies was extracted. These were summarised and organised by using a template, which included each study's research questions and key findings (see Table B.1 in Appendix

B for more detail). Only the data concerning the parents' perceptions, experiences, views, attitudes and beliefs were used for synthesising the findings of the included studies.

Data synthesis. In this review, an inductive thematic analysis approach was used to synthesise the findings of the included studies. Thematic analysis is primarily a qualitative method for analysing data gathered through interviews or observation using descriptive strategies (Braun & Clarke, 2012). The advantage of using thematic analysis is its flexibility. Thematic analysis is not constrained to a specific theory or technical rules. Therefore, it can be inductive or deductive in its approach to analysing data, and it is compatible with both realist and constructionist research paradigms (Braun & Clarke, 2006; Javadi & Zarea, 2016).

Thematic analysis can also be useful for synthesising the findings of qualitative research from various disciplines and professions in order to provide a systematic overview of the findings (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005). Inductive thematic analysis refers to a data-driven approach that develops coding from the existing raw data instead of using a set of codes developed from pre-determined ideas or theories (Braun & Clarke, 2012). It is found to be particularly useful for undertaking an interpretive approach to "synthesis while preserving the individual integrity of individual studies by remaining close to the primary data" (Dyer & das Nair, 2013, p. 4). A successful adaptation of inductive thematic analysis in the systematic review of qualitative studies has been demonstrated in a number of published studies (Bradshaw, Playford, & Riazi, 2012; Dyer & das Nair, 2013; Garcia et al., 2002).

The data synthesis procedures used in this review followed the five steps of thematic analysis recommended by (Braun & Clarke, 2006); (1) familiarisation with the given data, (2) identifying and generating initial codes from the data, (3) organising the identified codes to generate themes or patterns, (4) reviewing the themes through evaluating the validity of the identified themes, (5) refinement of the themes.

In order to become familiarised with the data, the results section of the included studies was read multiple times. The primary themes and sub-themes of each study were identified and tabulated with relevant verbatim quotes. From this, codes were generated and organised based on the direct quotations of the participants or the comments of the authors. A detailed matrix of codes presented in Table C.1 in Appendix C, describes the codes that were identified for the 14 studies included in this review. The identified codes were then compared and contrasted. The common themes or patterns across the identified codes were captured and grouped into new themes. For instance, the codes describing the positive relationship between parents and therapist, appreciation of therapist' experiences and knowledge, and easy accessibility and flexibility of the training programme were grouped together as they represented the factors that promoted parent's engagement in the parent-training programmes. It was then labelled as 'facilitating factors' and assigned as one of the major themes. A number of themes were generated, and they were presented alongside the participant's quotations taken from the original studies. The analyses were conducted independently by the primary reviewer, and the results were then reviewed by her supervisors to check for agreement.

Results

Characteristics of the included studies

A total of 14 studies were included in this review. All studies were published after 2004. A summary of the (1) study nationality, (2) methodology, (3) participant details, (4) data collection and analysis methods, (5) parent-training programme, and (6) study rigor is presented in Table 4.5.

Geographical location of studies. Seven studies [2, 3, 4, 5, 8, 12, 14] were conducted in United States (US), three in Canada [7, 11, 13], two [6, 10] in the United Kingdom (UK), and one each in India [1] and South Korea [9].

Table 4.5

Characteristics of the included studies

				Participant characteristics				Parent training Programme	
	Study	**Country**	**Methodology**	parents	Children's Age	**Data collection method**	**Data analysis**	**Type**	**Delivery**
1	Brezis et, al. (2015)	India	Qualitative	78 M & F pairs	2:3-10:6	The Five-minute speech sample	Thematic analysis	Parent-Child Training Programme (PCTP) (social communication)	In-person
2	Chlebowski et, al. (2018)	USA	Qualitative	29 parents (93% =M)	Mean=9.8	Focus groups (therapist) & Semi-structured phone interview (parents)	Grounded theory method based	An Individualised mental Health Intervention for ASD (AIM HI) (disruptive behaviours)	In-person
3	Donaldson et, al. (2011)	USA	Qualitative	10 F	3-8	Semi-structured interview	Analysed by line by line	Elder's Father-directed In-Home Training (social communication)	In-person
4	Foster et, al. (2013)	USA	Qualitative	10 M	4-10	Interview	No specified analysis method	Occupational Performance Coaching	In-person
5	Freuler, et al. (2014)	USA	Qualitative	13 M + 4 F (5 dyads)	3:3-3:10	Semi-structured interview	Thematic analysis	Parent coaching of Adaptive responsive teaching	In-person
6	Hodgson et, al. (2018),	UK	Qualitative	11 M, 1 M & 2 GrandM	3-7:11	Focus group	Framework analysis	Managing Repetitive Behaviours - Parent Group intervention	Group-based
7	Patterson & Smith (2011)	Canada	Qualitative	4 parents	2:4-3:1	Semi-structure interview & Focus group	followed a description of a book	The More Than Words -Parent Education programme (Group-based) (social communication)	Group-based
8	Wallisch et, al. (2019)	USA	Qualitative	8 parents	2:4-6:7	Semi-structure interview	Thematic contents analysis	Telehealth-delivered Occupation-based coaching	Online
9	An (2017)	South Korea	Mixed method	3 M & 1 GrandM	3-9	A semi-structure interview	Content analysis	Modified Occupational Performance Coaching (OPC)	In-person
10	Cutress & Muncer (2014)	UK	Mixed method	95 M & 25 F	3:5-9:7	Self-designed post-programme questionnaire	Content analysis	The Early bird Plus Programme (social communication)	In-person
11	Hodgetts et, al. (2013)	Canada	Mixed method	3 M & F pairs, 3 M	5-12	Semi-structured interview & Survey	Thematic analysis	Standard Stepping Stones Triple P for parents of children with ASD (Group-based)	Group-based
12	Pickard et, al. (2016),	USA	Mixed method	28 paretns, (96.8%=M)	12:7-6:1	Semi-structured interview & Survey	Rapid evaluation and assessment methodology & ground theory	Project ImPACT online, internet based, telehealth programme (social communication)	Online
13	Rivard et, al. (2017)	Canada	Mixed method	94 parents	2:2-4:9	Semi-structure interview & Survey	Systematic content analysis	Group based Parental Training and Coaching programme	Group-based
14	Stahmer, et, al. (2017)	USA	Mixed method	13 parents	0:8-1:9	Survey & Semi-structured interview	Ground theory	Project ImPACT	In-person

Methodology. A total of eight studies [1-8] adopted a qualitative research methodology while six studies [9-14] used a mixed method research design.

Participant characteristics. There was a total of 435 parents and three grandmothers of children aged 8 months to 12 years. The majority of the participants were mothers.

Data collection. Ten studies [2, 3, 4, 5, 8, 9, 11, 12,13, 14] employed a semi-structured interview to gather data. Four of them [11,12, 13, 14] used additional open-ended questionnaires. One study [7] used a semi-structured interview and focus group. The remaining three studies used a focus group [6], an open-ended narrative method [1], and a self-designed post-programme questionnaire with four open-ended questions [10].

Data analysis. Of the 14 studies, 11 studies specified the use of a recognised qualitative data analysis method. Of the eleven studies, two studies [1, 5] employed a thematic analysis, three studies [9, 10, 13] used a content analysis, one study [8] employed a framework analysis, one study [14] used ground theory, and the other [2] used a ground theory-based method. Of the three studies that did not use a recognised method, one study [4] did not specify any analysis method while two studies claimed that they used line-by-line coding [3] or based their method on a description of analysis in a cited book which was unable to be located [7]. All three studies employed a qualitative data collection method.

Type of parent-training. In six studies [1, 3, 7, 10, 12, 14], parent-training was based on interventions targeting the social-communication skills of children. Parent-training in three studies [4, 8, 9] were based on Occupational Performance Coaching (OPC). The OPC is an intervention based on the principles of Occupational Therapy and it is designed to support parents to achieve their own target goals in occupational performance for themselves and their child (Graham, Rodger, & Ziviani, 2009). Three studies were based on a behavioural management parent training programme that specifically targeted Restrictive and Repetitive Behaviours (RRB) [6] and disruptive behaviours [2, 11]. Parent-training in the remaining two

studies was described as training to support parents' interaction with their child by using responsive strategies [5] or ABA based strategies [13].

Parent-training delivery method. The parents in eight studies received a face-to-face individualised parent-training [1, 2, 3, 4, 5, 9, 10, 14]. The parents in four studies [6, 7, 11, 13] received group-based parent-training, and the parents in two studies [8, 12] received telehealth-based parent-training.

Study rigour. The MMAT was used to evaluate the methodological rigor of the included studies. Of the eight qualitative studies, seven studies [1, 2, 3, 5, 6, 7, 8] met all five quality rating criteria. This suggested that the overall rigor of the qualitative studies was strong and of a high quality. The remaining study [4] met two of the five quality rating criteria. The finding of this study was not derived adequately from the data, and the interpretation of the results was not substantiated by data. Moreover, there was a lack of coherence between the data sources, collection, analysis and interpretation.

Of the six mixed method studies, four met at least four criteria out of five [9, 11,12, 14], and were considered to have strong methodological rigor. The remaining two studies [10, 13] met fewer than three of the criteria for mixed-method studies. Both studies failed to provide an adequate rationale for using mixed methods. Also, the integration and interpretation of the qualitative and quantitative components were inadequate in both studies. However, it is important to keep in mind that one study [13] met all five quality criteria and the other [10] met three quality criteria in the qualitative study category. It was identified that the interpretation of the results in the study [10] was inadequate and the coherence between the data collection, analysis and interpretation was insufficient. Regarding the reporting of the result of the quality appraisal, the MMAT suggests reviewers present the ratings of each criterion instead of providing an overall score, when describing the quality of an individual study (Hong, Fàbregues, et al., 2018). A detailed description of the MMAT results is

therefore provided in Table A.1 in Appendix A. However, it is unwieldy for the readers and reviewers to comprehend the outcomes of the MMAT given the complexity involved in the process of appraisal. Therefore, providing a summary of the appraisal is considered necessary. Each study the MMAT appraisal is summarised in Table 4.6, below. In the table, the number of criteria that each study met are described. For example, if a study met three out of five criteria, it was given three stars (***). For mixed method studies, the number of rating in the mixed method component of the study was reported (See Appendix A for more detail).

Table 4.6

MMAT scores for included studies

Research design	**Included studies**	**MMAT scores**
Qualitative studies	[1] Brezis et, al. (2015)	*****
	[2] Chlebowski et, al. (2018)	*****
	[3] Donaldson et, al. (2011)	*****
	[4] Foster et, al. (2013)	**
	[5] Freuler, et al. (2014)	*****
	[6] Hodgson et, al. (2018),	*****
	[7] Patterson & Smith (2011)	*****
	[8] Wallisch et, al. (2019)	*****
Mixed method studies	[9] An (2017)	*****
	[10] Cutress & Muncer (2014)	**
	[11] Hodgetts et, al. (2013)	****
	[12] Pickard et, al. (2016),	*****
	[13] Rivard et, al. (2017)	***
	[14] Stahmer, et, al. (2017)	*****

Synthesis of the findings

As summarised in Table 4.7, three broad themes were generated from both qualitative and mixed-method studies: *facilitating factors, perceived barriers* and *outcomes of parent-training*. The first theme '*facilitating factors*' reflects the elements of parent-training programmes that facilitated and promoted positive engagement of parents in the training programme. The second theme *'perceived barriers'* represents the perceived barriers to

parents' participation in parent-training and implementation of PMI. The last theme '*outcomes of parent-training*' illustrates the outcomes and perceived benefits of parent-training reported by parents. Within each of the broad themes, a number of sub-themes were developed and presented.

Table 4.7

Themes and subthemes regarding parents' perception of parent-training programme

Themes	**Subthemes**
1. Facilitating factors	1.1 Therapist factors 1.2 Flexibility and accessibility 1.3 Benefits of group-based format
2. Perceived barriers	2.1 Difficulty coping with programme demands 2.2 Circumstantial challenges 2.3 Unmet needs of parents (informational, emotional and service needs)
3. Outcomes of parent-training	3.1 Acquisition of knowledge and skills 3.2 Changes in parents' perception of their child and themselves 3.3 Improved sense of well-being 3.4 Improved parent-child relationship

Theme 1: Facilitating factors. This theme describes the elements of parent-training programmes that provide a positive learning experience and promote parents' engagement in the training process. The identified elements are thought to be closely associated with facilitating parents' implementation of PMI with their child and their satisfaction with the training programme. A number of facilitating elements of parent-training were identified and grouped into four subthemes, which are briefly summarised in Table 4.8.

Table 4.8

Theme 1: Facilitating factors

Sub-themes	***Description***
1.1 Therapist factors	▪ Positive parent-therapist relationship is key for parents' satisfaction with parent-training programmes ▪ Being empathetic, non-judgemental, respectful, warm and friendly, and being open to parents' contributions is key characteristics of a therapist that contribute positive parent-therapist relationship

	▪ Parents valued therapist professional knowledge, expertise and their objectivity
1.2 Flexibility and accessibility	▪ Parents were appreciative of flexibility in scheduling appointment time
	▪ Parent expressed a high level of satisfaction regarding telehealth approach to parent-training, as it offered easy access to training
1.3 Benefits of a group-based format	▪ Group-training provided an opportunity for parents to be connected with other parents of children with ASD and support each other's learning

Subtheme 1.1: Therapist factors. In six of the included studies, parents discussed their relationship with a therapist in relation to their satisfaction with training (Chlebowski, Magana, Wright, & Brookman-Frazee, 2018; Freuler et al., 2014; Rivard et al., 2017; Wallisch, Little, Pope, & Dunn, 2019). In this review, the term 'therapist' is used to describe a coach or trainer of the parent-training programme for PMI. Freuler et al. (2014), in particular, emphasised the value of positive parent-therapist relationships in the process of parent-training, and claimed that it was a key to parents' buy-in to intervention. Parents in other studies described a collaborative and trusting relationship with the therapist as fundamental to their learning and engagement (Chlebowski et al., 2018; Foster, Dunn, & Lawson, 2013; Wallisch et al., 2019).

> *"*[W]*e had a relationship of trust, it is as if I was talking with a friend, she made me feel as a friend, as someone who I could trust, as someone who listens to me and is not criticizing or watching to see what I'm doing wrong or what I do wrong." (Chlebowski et al., 2018)*

> *"*[The intervention] *was very customized to our life and our routine and how we did things. It was awesome, instead of being like 'here's this technique make it work for you'. It was, 'what did you do? Oh, maybe we can improve upon that. Let's try a few different strategies." (Wallisch et al., 2019)*

Parents in several studies identified characteristics of the therapist as important in promoting a positive parent-therapist relationship. These characteristics included being empathetic, non-judgemental, respectful, warm and friendly, as well as being open to parents'

contributions (Chlebowski et al., 2018; Foster et al., 2013; Rivard et al., 2017; Wallisch et al., 2019).

> *"I feel like my opinion or whatever I said* [therapist] *respected and valued my input." (Wallisch et al., 2019)*

> *"I felt comfortable asking* [the therapist] *questions, 'what does this mean? And I didn't feel judgment from her, you know telling me I'm doing something wrong… you kind of get that a lot. We're always kind of nervous because we're trying our best, you're always hoping you're doing it right… so I feel working together as a team was probably my favourite part." (Wallisch et al., 2019)*

Therapist professional knowledge, expertise and their objectivity were identified as other factors that promoted parents' positive training experiences (Foster et al., 2013; Rivard et al., 2017; Stahmer et al., 2017; Wallisch et al., 2019)

> *"It felt to me like she knew exactly what she was doing and I felt really comfortable that she was going to guide us in the right direction and she did a really good job." (Stahmer et al., 2017)*

Subtheme 1.2: Flexibility and accessibility. Parents were particularly appreciative of the training programmes that offered an alternative training time, which included weekends and evenings, to fit in better with the busy lives of the families (Freuler et al., 2014; Hodgson et al., 2018). This finding coincides with reports from Rivard et al. (2017) and Stahmer et al. (2017), whereby parents suggested the needs for improved flexibility in scheduling and accessibility of the programme.

Using telehealth-based parent-training programmes such as Project-Impact online and telehealth delivered occupation-based coaching as a format for the delivery of parent-training was found to be particularly beneficial in this respect. Parents who received telehealth parent-training endorsed its ease of accessibility as compared to parent-training delivered in person

and reported how well it fitted with their family circumstances and needs (Pickard et al., 2016; Wallisch et al., 2019):

> *"it's very difficult to go to offices and sit for an hour, get everybody out of the house and somewhere on time. so that was really convenient being able to do* [telehealth] *from home, and it only took an hour, it didn't take an hour plus travel time." (Wallisch et al., 2019)*

> *"Because it's just really hard with a lot of these other therapies and stuff. It's just so hard to get an appointment that's in the evenings or you know on the weekends....it just doesn't happen so it's hard to fit everything in, so at least you can … learn how to do all this kind of stuff at home or wherever." (Pickard et al., 2016)*

Subtheme 1.3: Benefits of a group-based format. Parents identified a small group-based format as a positive factor in their training experience. Parents who attended group-based parent-training reported that sharing experiences with other parents who were in the same situation and getting support from them was particularly valuable (Cutress & Muncer, 2014; Hodgson et al., 2018; Patterson & Smith, 2011):

> *"It is essential! Not only do you gain greater understanding about autism but meeting other parents in a similar situation really helps." (Cutress & Muncer, 2014)*

> *"It helped me to interact with the other families. It taught me that I wasn't alone, there are many people going through the same struggles. At the beginning, I thought I was basically by myself …, dealing with this but actually it's nice to have a group setting and to have other people views and opinions..." (Patterson & Smith, 2011)*

Parents also reported that group-based training provided an opportunity for them to learn from each other (Hodgson et al., 2018):

> *"I would say don't change that, you get more from the group that what you would get one-on-one, if you were to sit and talk about something just one-on-*

one to somebody you probably won't expand on all the things whereas you get ideas from all the people jumping in as we do."

The desire to have an opportunity to connect with other parents was cited by other parents who attended one-on-one parent-training as well (Freuler et al., 2014; Stahmer et al., 2017).

Interestingly, Patterson and Smith (2011) reported that having parents of children with varying levels of communication skills in the same group led some parents to compare their child with other children in the group, which in turn led them to feel frustrated:

"It kind of felt personal that your child wasn't THERE at that time ... you kind of felt like 'oh my god some kids are there and your kid's not' and 'why isn't he doing anything?' you kind of feel bad."

Theme 2: Perceived barriers. This theme describes the parents' perceived barriers to engaging in parent-training and implementing PMI. Many studies reported a range of perceived challenges that parents experienced during the training, which included difficulty coping with programme demands, circumstantial challenges, and unmet needs of parents (informational, emotional and service needs). The identified challenges appeared to be hindering parents' abilities to seek parent-training programmes or make meaningful changes for themselves as well as their child during the training.

Table 4.9

Theme 2: Barrier factors

Sub-themes	***Description***
2.1 Difficulty coping with programme demands	▪ Parents reported difficulty comprehending training content, completing weekly homework, finding time to read, and finding time to practise learnt strategies
2.2 Circumstantial challenges	▪ Difficulty attending certain training sessions due to work commitment
2.3 Unmet needs of parents	▪ Unmet informational need; parents have limited knowledge of ASD ▪ Unmet emotional needs; parents need emotional supports as it is difficulty to cope with the initial diagnosis their child ASD ▪ Unmet service needs; prior to the diagnosis, parents experience difficulty validating their initial concerns for their child's

development with health professionals or members of family. After receiving the diagnosis, parents are given limited information regarding the available services for their child with ASD

Subtheme 2.1: Difficulty coping with programme demands. Parents reported a number of challenges associated with coping with programme demands during their participation. This included difficulty comprehending training content, completing weekly homework, finding time to read, and finding time to practise learnt strategies (Freuler et al., 2014; Hodgson et al., 2018; Patterson & Smith, 2011; Pickard et al., 2016; Rivard et al., 2017; Stahmer et al., 2017). Patterson and Smith (2011) reported that parents perceived difficulty coping with the large contents of the training and felt overwhelmed as a result:

> "[As a parent of newly diagnosed toddler] *applying all those, I mean learning, reading, applying all those strategies at the same time especially at the beginning it's very difficult."*

Some parents reported that coping with weekly homework was challenging and questioned its value in the training process (Stahmer et al., 2017);

> *"I didn't see a lot of value in the homework to be completely honest with you. I felt it was busy work, and if you see my book, you'll see it's hardly filled out."*

Hodgson et al. (2018), on the other hand, reported that most parents described homework was acceptable and feasible, even though it was time-consuming:

> *"I think diary keeping is quite, it's quite hard going anyway, but it was very beneficial cos there were little things that you think 'oh I maybe wouldn't have brought into the session if I hadn't have written it down'. It was beneficial but it was a little bit of a chore, you know…"*

Subtheme 2.2: Circumstancial challenges. One study described the difficulties that parents had inaccessing the in-home supports provided during the day due to their work commitments. As a result, the parents reported that they felt as if they "*lost out on the coaching*" or "*feeling left out.* " It also placed an extra burden on the partners of those parents

as they had to learn from their partner. In response to this, Patterson and Smith (2011) claimed that parent-training may need to consider a way to accomodate parents who are working outside of the home:

> *"*[F]*or fathers or mothers that do work during the day who miss out on all that stuff, it would be nice to have a support group … just to get that additional help."*

***Subtheme 2.3: Unmet needs of parents*.** Patterson and Smith (2011) reported that unmet emotional, informational and service needs of parents were identified as barriers for parents in seeking and engaging in the parent-training programme. It was thought that these unmet emotional and informational needs might hinder parents' abilities to learn and make changes for themselves as well as for their child. These unmet service needs may prevent parents from seeking support from parent-training programmes.

Unmet informational needs. In three studies, parents reported that they struggled to receive any information regarding their child's ASD diagnosis or support services for their child (Chlebowski et al., 2018; Hodgson et al., 2018; Patterson & Smith, 2011).

> *"There's a lot of parents do not have information when they* [their children] *first get diagnosed with the autism." (Chlebowski et al., 2018)*

> *"I didn't know, I knew the things that were challenging me but I didn't know they were repetitive behaviours." (Hodgson et al., 2018)*

In one study, parents reported that participating in parent-training with limited knowledge of ASD was particularly challenging and addressed the need for psychoeducation before receiving parent-training to implement PMI with their child (Chlebowski et al., 2018);

> *"What happens is that, it's because of a lack of information from the parents not knowing, and when the therapist starts sayin gthings, the people get confused becaue they do not know."*

Unmet emotional needs. Several studies reported the emotional struggles that parents experienced as a result of receiving their child's initial diagnosis of ASD. For instance,

parents were described as having difficulty accepting the initial diagnosis (Patterson & Smith, 2011), developing concerns for their child's future and feeling "*scared*" or "*anxious*" (Donaldson, Elder, Self, & Christie, 2011), and being "*desperate for advice and supports"* to manage their child's behaviours (Hodgson et al., 2018). One study reported that providing emotional supports for parents may facilitate parents' engagement in training and implementation of PMI for their child (Patterson & Smith, 2011). One mother in the study stated that:

> "*I think that if the parents are emotionally looked after… maybe they'll be better off with their children. Maybe have better response to the communication or things like that.*"

In addition, An (2017), reported that parents struggled to cope with a lack of support from family and community due to the social stigmatisation of autism in Korea. The stigmatisation of autism led the parents to avoid any social interactions with their family and friends, and limited the activities that they engaged in, in public. As a result, the parents felt socially isolated and overwhelmed with the burden of care for their child.

> *"*[M]*y husband and I did not want others to know about* [my child's] *diagnosis. So I don't have anyone to help me look after* [my child]*. I can't afford to get sick since I moved away from my family."*

Unmet service needs. In three studies, parents reported that they had unmet service needs (Freuler et al., 2014; Hodgson et al., 2018; Pickard et al., 2016). For instance, Freuler et al. (2014) reported that parents experienced a lack of support when they began to raise concerns about their child's development. It was pointed out that parents struggled to validate their concerns with healthcare and early intervention professionals as well as with members of their own family. The parents in this study reported that their GP or paediatricians showed a lack of interest and were "*dismissive*" of their concerns.

"If we had not gotten into the study, by now we would have heard 'no' so many times that we would have given up trying to get anybody to sort of see what we were seeing."

Other studies (Hodgson et al., 2018; Pickard et al., 2016) reported that there was a lack of information regarding available resources/services provided for parents at the time of their child's initial diagnosis of ASD.

"And so I mean it would have been helpful to be able to talk to our paediatrician or the doctors because everybody tells you that you have to start intervention and early intervention is key, but nobody gives you anything other than 'well you need to do early intervention'. Well where the hell do you find that?" (Pickard et al., 2016)

"…just desperate for anything, help from anybody I was willing to take." (Hodgson et al., 2018)

Theme 3. Outcomes of parent-training. This theme illustrates the outcomes and benefits of parent-training perceived by parents after participating in a parent-training programme to implement PMI for their child.

Table 4.10

Theme 3. Outcomes of parent-training

Sub-themes	***Description***
3.1 Acquisition of knowledge and skills	▪ Parents reported that increased knowledge of ASD and an acquisition of new skills as a positive outcome of parent-training
3.2 Changes in parents' perception of their child and themselves	▪ Increased knowledge of ASD helped parents to understand their child better ▪ Parents reported positive changes in how they view their child which was described as more optimist and realistic ▪ Parents reported changes in how they interact with their child to advocate and facilitate their child's learning and development
3.3 Improved sense of well-being	▪ Parent-training helped parents to gain a sense of empowerment ▪ Improved sense of empowerment helped parents in decreasing the perceived level of stress and increasing the feelings of optimism
3.4 Improved parent-child relationship	▪ Parent-training improved parent-child relationship by helping parents to communicate, engage and interact with their child better

Subtheme 3.1: Acquisition of knowledge and skills. Parents were most likely to cite an increase in their knowledge of ASD and an acquisition of new skills/strategies as positive outcomes of training. The increased knowledge of ASD through training included having a better understanding of symptoms of ASD, communication difficulties and sensory sensitivity as well as the complex and life-long nature of the disorder (Cutress & Muncer, 2014; Freuler et al., 2014; Hodgson et al., 2018). Hodgetts, Savage, and McConnell (2013) also reported that parents gained insight into the function of disruptive behaviours in children with ASD through the SSTP parent-training.

Regarding the acquisition of new skills, parents cited that an ability to analyse and reflect was identified as one of the most effective strategies they learnt through training (Foster et al., 2013; Hodgson et al., 2018):

> *"*[Y]*ou think as well about your own behaviour, and that's what was highlighted, your behaviour, even though you try to hold things in… and how much you really need to pay more attention to what you were doing, almost analysing yourself, as well as your child. I found that really interesting and helpful, unusually helpful."* (Hodgson et al., 2018)

Some parents reported that learning to follow their child's lead was particularly effective (Donaldson et al., 2011; Stahmer et al., 2017):

> *"I think that the most useful thing about the training was learning really how to follow your child's lead … to get down on their level and to maintain face to face contact." (Stahmer et al., 2017)*

Subtheme 3.2: Changes in parents' perception of their child and themselves. The increased knowledge of ASD and acquisition of new skills enabled parents to understand their child better (An, 2017; Brezis et al., 2015; Cutress & Muncer, 2014; Hodgson et al., 2018; Rivard et al., 2017). An (2017) identified "*new learning*" as one of the main themes, and reported that all parents in the study said they "*realized how little they knew about their*

child, about their needs, and how to assist them" (p.5). For instance, one mother in the study thought her child had no "*personality because all he did was make monstrous sounds and rock himself all day."* Learning about the sensory needs of children with ASD helped her to understand her child and his needs better.

Development of a better understanding led to a shift in parents' perceptions of their child (An, 2017; Brezis et al., 2015; Cutress & Muncer, 2014). According to An (2017), one mother stated that her view of her child as "*my poor baby with a disability who can't do anything*" changed to "*my child who can be assisted to participate in daily activities*" as a result of attending parent-training. Parents also expressed that parent-training helped them to view their child as more capable and it led them to have higher expectations of their child:

> *"*[M*]y husband's attitudes and my attitude towards our son has changed since the learning sessions. We now expect* [our son] *to participate in daily activities much more… The funny thing is that with just that change in attitude,* [our son] *is doing so much more and is so much more responsive."*

Similarly, parents in the SSTP programme reported that they felt "*sorry*" for and "*gulity*" about disciplining their child before attending the training (Hodgetts et al., 2013). The training changed their perception toward their child and their response to their child's behaviours:

> *"It's like 'Yes, just because they have a disability doesn't mean that they can get away with murder or that you can't have expectations for a certain way to behave."*

> *"Now he's not the one in charge… we gave him everything before… Now we're the ones in charge."*

Parents also expressed more optimistic and realistic views of their children (Brezis et al., 2015; Hodgson et al., 2018):

> *"*[E]*arlier I was so worried, because my son cannot even recognize me. But now [I understand that] he is slow, yet he will be able to learn later."* (Brezis et al., 2015)

> *"I realised that his behaviour…wouldn't just stop, and while we've seen marked improvements, it wasn't going to go away overnight so I think that, for me, that was the biggest mind-set of all, and how to deal with that… he's always going to have these challenges, it's more how you adapt around him, how you deal with that, rather than making it go away."* (Hodgson et al., 2018)

Brezis et al. (2015), also commented that, in post-training narratives, parents were more likely to report positive future outlooks for their children. This was reflected by increased parental reporting about their desire for their child to live an independent life and attend a regular school.

Parents also reported a shift in how they viewed themselves and changes in how they interacted with their child. Parents began to identify themselves as a critical in facilitating children's learning and development, while acknowledging a need for change in to the way in which they interact with their child (Cutress & Muncer, 2014). For instance, parents stated that "*…our behaviour principally, i.e., as parents, has to change to help* [children]*" or "it is my families communication that needs to change"* in order to accommodate their child's needs.

Parents became more aware of their own behaviours and how they may impact on their child (Cutress & Muncer, 2014; Foster et al., 2013; Hodgson et al., 2018; Wallisch et al., 2019):

> *"I'm more patient with him because I realize that he's not doing anything wrong and we can problem solve and try different strategies to make something work." (Wallisch et al., 2019)*

> *"…adults tend to overuse language-I did it as well, a lot. Now I'll try to keep it as simple as possible."* (Cutress & Muncer, 2014)

Subtheme 3.3: Improved sense of well-being. An increased sense of well-being was another sub-theme that appeared strongly in relation to the acquisition of ASD knowledge and new skills. In six of the included studies, parents described "*feeling empowered*" or "*I will be able to help my child*" as a result of attending parent-training, and expressed an increased sense of positivity and confidence in their ability to problem solve (Cutress & Muncer, 2014; Foster et al., 2013; Hodgetts et al., 2013; Pickard et al., 2016; Stahmer et al., 2017):

> *"The* [therapist] *gave me the confidence to sit down with my child and figured out what my child wanted." (Wallisch et al., 2019)*

> *"feel more confident to tackle the issues…we know that we're working through issues in the right way." (Hodgson et al., 2018)*

Parents who described parent-training as "*empowering*" described a sense of helplessness prior to engaging in parent-training (Hodgetts et al., 2013; Pickard et al., 2016):

> *"…from a family stand-point, I felt a little helpless. Like what do I do? And you know of course they have intervention outside of the home, going to this therapist and that, but when they come home a parent can be like I don't have the knowledge. So, having something like this, I feel like I have power to really help my kid now." (Pickard et al., 2016)*

Stahmer et al. (2017) reported that developing a sense of empowerment was a key factor in parents' satisfaction and beliefs about the acceptability of parent-training. A parent in the study reported that:

> *"It was incredibly useful … because we wanted to be involved … when we got his diagnosis, we didn't want to just lay down and just let someone else deal with it, we wanted to be part of it and do something and not just feel like we couldn't contribute. So that part for me was that most valuable, because even though he's not meeting with* [the therapist] *anymore, I know what he should be doing and I know what I can do to help. So for me it's the best."*

Feeling empowered had a positive influence on parents' psychological well-being by decreasing their perceived levels of stress and increasing feelings of optimism (An, 2017; Cutress & Muncer, 2014; Hodgetts et al., 2013; Rivard et al., 2017; Stahmer et al., 2017):

> *"[I]n the beginning when you get that diagnosis and you don't know a lot about it and you don't know what you can do and it's really scary. And after you go through the training you just feel like you can handle this. And there are things you can do to contribute. So I think that helps with the stress." (Stahmer et al., 2017)*

In addition, Hodgetts et al. (2013) reported that parents in the SSTP parent-training consistently identified that focusing on positive aspects of their child's behaviour had a positive impact on their psychological well-being. According to the authors, many parents of a child with ASD experience constant difficulty managing negative behaviours which was placing a strain on their psychological well-being.

Subtheme 3.4: Improved parent-child relationship. Parents frequently cited an improved parent-child relationship as an outcome of attending parent-training. It was described that parent-training enabled parents to communicate, engage and interact with their child better (An, 2017; Donaldson et al., 2011; Pickard et al., 2016; Stahmer et al., 2017):

> *"we owe a lot to the programme just in being able to know how to play with our son and engage him and interact with him and through that, a definite bond has formed that I did not feel that I had with my son before we started the programme." (Stahmer et al., 2017)*

> *"Yeah, truthfully it helped me to interact more with him…" (Pickard et al., 2016)*

> *"The best thing about the programme is that it made me make time to spend and focus on my son…. I think the programme has drawn he and I closer together because he sees that I am more than just a disciplinary figure. It's kind of brought me more into the nucleus* [of the family] *than I probably was before and it's great." (Donaldson et al., 2011)*

Discussion

The primary goal of this qualitative systematic review was to provide a comprehensive review of the literature that has evaluated parents' perceptions and experiences of PMI. The aim of this review was underpinned by two research questions; (1) *what are perceived facilitators and barriers to parents' engagement in PMI, especially in relation to the parent-training component?* and (2) *what are the outcomes or benefits of PMI as perceived by parents?.*

A total of 14 studies were included in this review. The MMAT was used to assess the methodological rigor of the included studies. The result indicated that the majority of these studies had strong methodological rigor, especially in relation to the five criteria for qualitative studies set out in the MMAT. Seven out of eight qualitative studies and five out of six mixed-method studies met all five criteria. It was identified that, in the remaining one qualitative study (Foster et al., 2013) and one mixed method study (Cutress & Muncer, 2014), the interpretation of the results was not sufficiently sustained by the data. The two studies also lacked coherence between qualitative data sources, collection, analysis and interpretation. In addition, the findings of Foster et al. (2013) were inadequately derived from the data. However, no systematic differences were found between these two studies and the others in terms of themes that were generated. This may reflect the current understanding in qualitative research that there is no clear evidence regarding the positive relationship between the methodological quality and robustness/trustworthiness of the findings (Dixon-Woods et al., 2005; Dixon-Woods et al., 2006).

To synthesise and integrate the findings of the included studies, a thematic analysis was employed in this review. Three major themes were identified, namely (a) *facilitating factors*: (b) *perceived barriers*: and (c) *outcomes of parent-training*. In relation to the theme *facilitating factors*, therapist's personal attributes and ability to build a positive relationship

with parents; therapist's clinical skills, flexibility and accessibility of the training program; and the use of a group-based format were found to promote positive engagement of parents in the PMI training process. Within the theme relating to *perceived barriers*, difficulty coping with programme demands and the unsuitability of training times for working parents were identified as the challenges parents often faced with when engaging in parent-training. It was also found that parents' unmet informational, emotional and service needs hindered parents' abilities to seek supports from PMI and/or make meaningful changes through PMI. The theme *outcomes of parent-training* suggested that parents gain new knowledge and skills through training. Such gains direct parents to view themselves and their child with more optimism and enable them to achieve a better sense of wellbeing. This in turn resulted in improvement in the parent-child relationship.

Facilitators and barriers to PMI

The first objective was to identify what parents perceive to be the factors that facilitated or challenged their engagement in PMI, especially in relation to the parent-training component. The findings of this review suggest that parents generally value therapist related factors as important elements of parent-training that promoted their engagement and satisfaction with the training. This finding is not surprising considering the extensive empirical research indicating the positive impact of the therapist's personal characteristics and skills on the therapeutic alliance (Ackerman & Hilsenroth, 2003). In relation to the existing research, a similar finding was reported in a study that provided an overview of PMI in the field of ASD, where the author described the characteristics of an effective parent-training educator (Brookman-Frazee, Vismara, Drahota, Stahmer, & Openden, 2009).

The finding that parents' had a preference for flexible and accessible training programmes aligns with the research on parenting programmes for parents of children with normative development. A review that gathered evidence across different parenting

programmes serving a wide range of populations reported that conducting training in a convenient location, having flexibility in scheduling, providing extra support for childcare or transportation may increase the engagement of parents (Axford, Lehtonen, Kaoukji, Tobin, & Berry, 2012).

Interestingly, parents in studies where parent-training was delivered in-person expressed a need for more flexibility and easy accessibility. On the other hand, the parents in telehealth studies reported the benefits of the flexibility and easy accessibility of the training format as the most satisfactory aspect of their experience. The relatively small number of studies included in this review limits the conclusions that are able to be drawn about which type of delivery method parents may prefer. It is however possible to infer that, from the perspectives of parents, telehealth-based parent-training may be a useful alternative to the face-to-face format of parent-training. Although there are numerous research studies on the feasibility and accessibility of telehealth-based parent-training for parents of children with ASD (Boisvert & Hall, 2014; McConachie & Diggle, 2007; Parsons, Cordier, Vaz, & Lee, 2017), it appears that there are no studies examining how parents compare telehealth based parent-training to the traditional in-person parent-training. Further investigation regarding this topic is warranted to clarify whether parents prefer parent-training delivered via online platform as compared to in-person.

A group-training format was identified as another factor that facilitated parents' engagement in training. It is well known that parents of children with ASD face a number of challenges due to stigma associated with ASD, which in turn results in parents experiencing rejection and feelings of isolation, together with a reduced sense of parenting confidence (Kinnear, Link, Ballan, & Fischbach, 2016; Mandell & Salzer, 2007). Having to be connected with other parents with similar experiences through training appeared to have a positive impact on restoring parents' sense of belonging and parenting confidence.

In relation to *perceived barriers*, parents identified the challenges associated with unmet emotional support needs and how this hinder their abilities to engage in parent-training. This finding suggests the need for providing additional service to support parents' emotional well-being may enhance parents' engagement in parent-training. Research has found that teaching parents to manage their own behaviours and emotions using specific cognitive-behavioural techniques resulted in positive psychological outcomes for parents (Bitsika & Sharpley, 1999; Blackledge & Hayes, 2006; Shaffer & Minshawi, 2014). Parents' positive perception regarding group-based training suggests that providing opportunities to meet with other parents in the training is an effective way to support parents' emotional well-being as well as to enhance their engagement and satisfaction with PMI.

According to Prata, Lawson, and Coelho (2018) and Steiner, Koegel, Koegel, and Ence (2012), PMI is underutilised in that only one quarter of parents of children with ASD use it in the community setting. The findings of this review regarding the perceived challenges or barriers of parent-training may provide a useful reference for ways to improve parents' engagement in parent-training. The perceived challenges frequently reported by parents in the included studies were difficulty coping with programme demands, incompatibility of the training schedule for working parents and the parents' prior experiences of the lack of informational and emotional supports available for them.

The findings regarding parents' perceived difficulty coping with programme demands suggests that the contents of some parent-training programmes may be too complicated or time-consuming for parents could cope with. However, it is important to note that, although parent-training with simpler protocols can produce better intervention adherence, the training programmes with complex and multiple training components may produce better overall outcomes for children (Wainer & Ingersoll, 2013). In order to clarify whether the benefits of simplifying the training process to enhance parents' engagement outweigh the benefits

produced by incorporating complex and multiple training components, further research is necessary to explore the relationship between the complexity of the parent-training model, parents' fidelity and the overall outcomes of parent-training.

It was interesting to note that the parents' difficulty coping with programme demands was reported in studies where parent-training targeting core-symptoms of ASD was employed, but not in the studies where OPC was used. Parent-training based on OPC aims at training parents to support children's participation in everyday activities (Simpson, 2015). Parent-training for core-symptoms of ASD, on the other hand, aims at training parents to learn a specific set of techniques to intervene in the symptoms of ASD in order to improve children's behavioural or developmental skills. Although further investigation is necessary due to the small number of studies relating to OPC in this review, the differences in theoretical and practical approach to training in OPC may explain why parents in the OPC based parent-training reported no difficulties in coping with programme demands.

Drawing from the discussion presented in this section, the two components of the theme *facilitating factors* and *perceived barriers* appeared to be inter-related in that certain facilitating factors may support parents to overcome identified barriers. The relationships between the themes and subthemes are represented in Figure 4.2. The dotted lines between the subthemes *facilitating factors* and *perceived barriers* represent the connection between the two. The white square box on the dotted line describes the suggestions made by parents that reflect how the identified barriers can be mitigated to facilitate positive engagement and perception of PMI amongst parents.

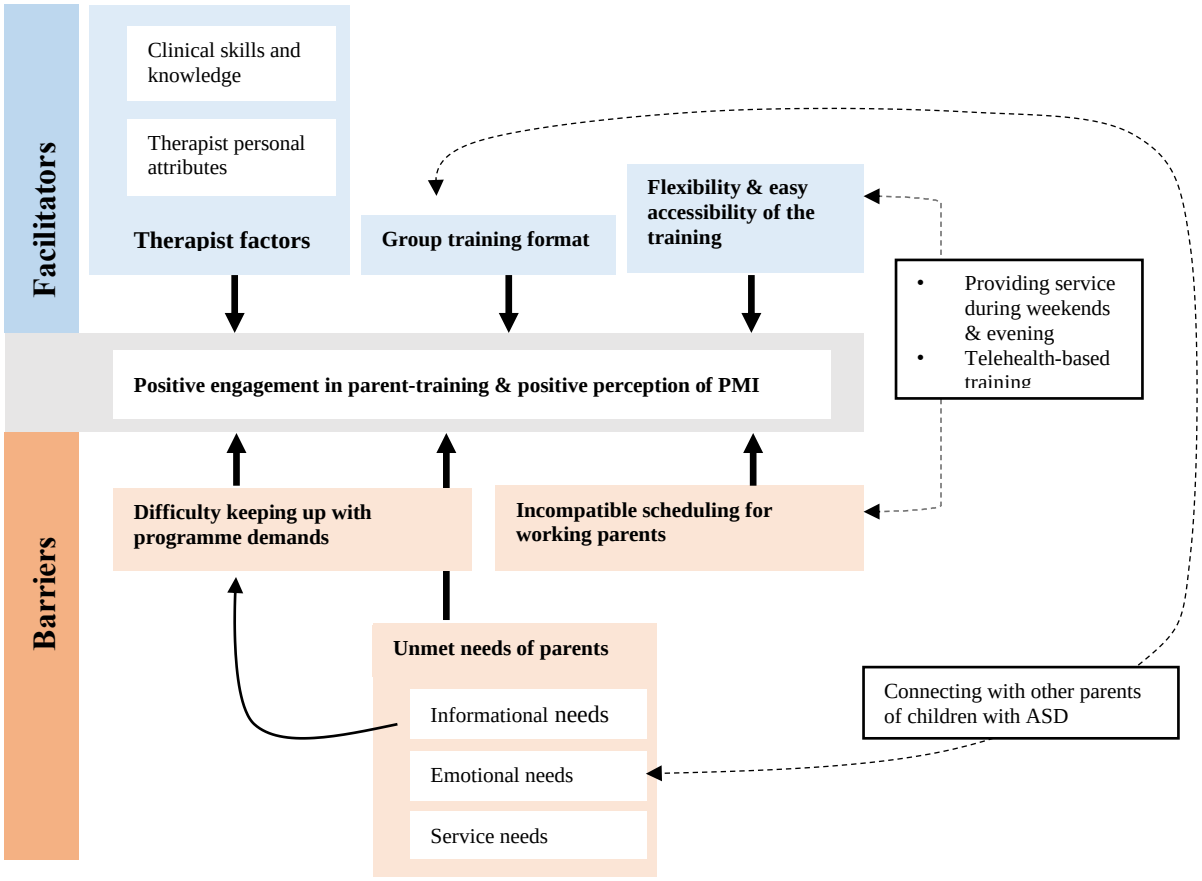

Figure 4.2. The relationships between the subthemes of *facilitating factors* and *perceived barriers*.

Perceived outcomes of PMI

The second objective of this review was to explore and summarise the outcomes of PMI from the perspectives of parents. Four subthemes were identified under the theme *outcomes of PMI*: (1) acquisition of knowledge and skills, (2) changes in parents perception of their child and themselves, (3) improved sense of wellbeing, and (4) improved parent-child relationship. In general, the findings of this review are consistent with the reviews of quantitative studies. A systematic review of PMI for young children with ASD reported a significant improvement in parent-knowledge amongst parents who received parent-training (McConachie & Diggle, 2007). A positive improvement in parent-child interaction was identified as a result of PMI in a systematic review of RCT of early interventions for children with ASD (Oono et al., 2013). Similarly, a positive enhancement in parent's responsivity to

their child and a notable improvement in child's social engagement with their parents were reported a result of parent-training in a literature review of PMI for young children with ASD (Beaudoin et al., 2014).

This review also revealed that parents perceived a reduced level of stress as a result of parent-training. However, the quantitative data regarding the relationship between parent-training and reduction in stress are largely inconclusive. Some studies reported a decrease in parent stress as a result of parent-training (Estes et al., 2009), while some reported that the impact of training on parental stress was not statistically significant when analysed using quantitative data (McConachie & Diggle, 2007; Schultz, Schmidt, & Stichter, 2011). The discrepancy observed between the studies may be explained by one of the findings of this review. Parents in the reviewed studies identified that the improved sense of empowerment contributed to a reduction in the level of stress relating to parenting children with ASD and restored their sense of competence as parents. This finding infers that the types of parent-training that improves parents' sense of competency may be more effective in reducing parent stress than the others. Further research to examine the relationship between self-efficacy and stress associated with parent-training is needed to confirm this hypothesis.

In the reviewed studies, parents described a positive parent-child relationship as one of the main benefits of parent-training. Interestingly, parents often described improvements in their relationships, with reference to the changes that parents were able to make through the training. For example, parents reported that the knowledge and skills taught in the training helped them to see themselves and their child differently, and it also helped them to feel confident and competent as a parent. This changed the way parents interacted with their child, which in turn led to perceived improvements in the quality of the parent-child relationship.

Based on the outcomes of this review, it is possible to presume that the positive impact of parent-training may occur in three levels. It is hypothesised that the knowledge and

skills gained through parent-training enhanced parents' perception of themselves and their child as well as their sense of empowerment and well-being. This in turn resulted in improvement in the parent-child relationship. This is presented in Figure 4.3.

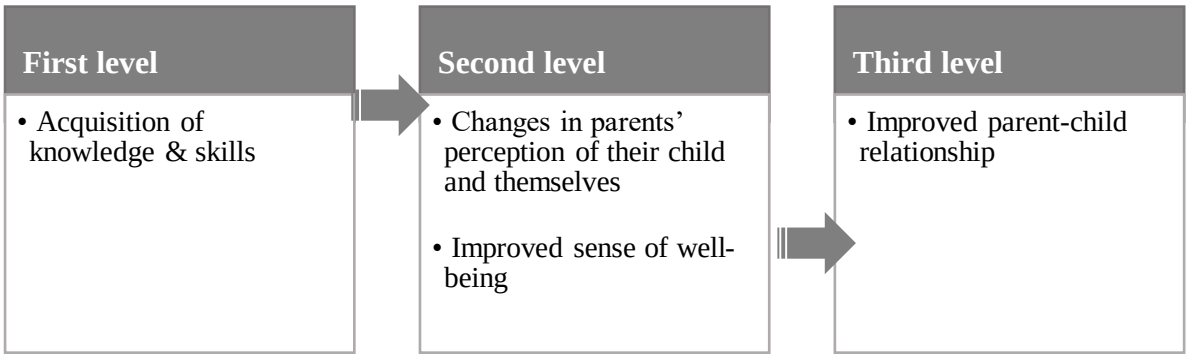

Figure 4.3. The outcomes of parent-training in three levels

Strengths and limitations

As described in the previous chapter, this is the first qualitative systematic review of parents' perception of PMI. Whilst there is substantial research investigating the effectiveness of PMI, there is comparatively limited research regarding parents' perceptions of PMI. This review has fulfilled this research gap by providing a comprehensive overview of how parents perceive and experience PMI.

This review also has some limitations that need to be addressed. First of all, the quality assessment of the included studies was limited to one reviewer. Although I sought advice from my supervisors, the appraisal was not conducted independently by my supervisors and compared with mine. Hence, there is a possibility that the outcome of the quality appraisal may differ if multiple reviewers assessed the included studies independently and discussed the appraisal to reach consensus. Moreover, the search and screening of studies for this review were completed by the author of this review only, and reliability of data extraction was not conducted. It is possible that appropriate articles might have been missed in the process. However, it is important to acknowledge that the process of the systematic

search strictly followed the comprehensive and systematic inclusion and exclusion criteria to minimise the occurrence of bias. Moreover, an additional set of criteria for the MMAT was created to enhance the critical appraisal of the included studies.

Secondly, there was a great degree of variation in terms of the type and delivery method of parent-training among the included studies. The training provided for parents varied in that some addressed core symptoms of ASD (social-communication) or managing RRB or disruptive behaviours, while others focused on enhancing parents' interaction with their child. In most studies, the training was based upon the behavioural intervention approach, but some were based on OPC. Also, the delivery method for training differed across the studies. Some studies employed a group-based format of training, while the others provided an individual training via in-person or home-based video telehealth modality. A wide range of parent-training in the included studies meant that the data relating to any one area was limited. For instance, most of the subthemes were derived from three to six studies, which were fewer than half of the included studies. Although parents provided valuable insight regarding their experiences of the particular parent-training they received in each of the included studies, it is possible to assume that more consistent themes across studies may have emerged if the studies provided similar type of parent training.

However, it is interesting to note that the advantage of such diversity in type, delivery method, format and theoretical grounding of parent-training in the included studies may promote the generalisability of the findings. In other words, the common themes of what parents value or dislike about parent-training can be useful for various types and forms of PMI regardless of its conceptual orientation or focus of intervention.

Furthermore, most studies in this review were conducted in the US, UK, and Canada; the majority of the participants were mothers. As a result, there is a concern that the findings of this review may be predominantly representative of Caucasian mothers of children with

ASD. While it is important to acknowledge that the search limitation applied for the English language may have contributed to this problem, it also highlights that there is a clear lack of information about how fathers or parents of different ethnic background may perceive and experience PMI. Future research with a diverse population in terms of ethnicity and gender is needed to better understand how parents perceive and experience PMI and to provide useful information to facilitate the development of PMI.

Lastly, this review employed thematic analysis as a tool to synthesise the findings of the included studies. While it is useful in summarising the themes reported in the primary studies, the synthesis produced with the thematic analysis is less interpretive than other methods for qualitative synthesis such as meta-ethnography (Britten et al., 2002) or thematic synthesis (Thomas & Harden, 2008). As addressed by Dixon-Woods et al. (2005, p. 45), thematic analysis is limited in generating "higher order thematic categories" beyond what is reported in the primary studies.

Implications of the findings and future research

PMI is highly valued by parents of children with ASD as one of the most effective and useful intervention for their child. The findings of this review provide insight into what aspect of parent-training contributed or challenged parents' perceptions of PMI, as well as the perceived outcomes of PMI. With a particular reference to the theme *facilitating factors* and *perceived barriers*, it is recommended that the developers and practitioners of PMI should consider: (a) the value of therapist factors in relation to parents engagement in parent-training; (b) the importance of offering flexible scheduling; (c) the benefit of providing opportunities for parents to interact with other parents of children with ASD; and (d) the importance of identifying and meeting the needs of parents such as providing emotional supports or psychoeducation during training.

This review also confirms the scarcity of qualitative research on parents' perceptions or experiences of PMI. Despite the large number of studies regarding PMI in the field of ASD, there were only 14 studies to be included in this review. Seeing the value of understanding the user perspectives in the development of PMI or any intervention for human subjects, it is recommended that future research consider including an in-depth qualitative research component to explore how parents perceive and experience PMI.

Considering the relative infancy of research related to parents' perceptions of PMI, a more concrete research effort is necessary to strengthen and expand the findings of this review. One recommendation for future researchers is to consider utilising a more inductive approach. Most studies in this review were based on a semi-structured interview or focus group governed by a specific set of questions that stemmed from social validity perspectives. Taking an inductive approach may provide novel insight into parents' perspectives that were not otherwise possible to be elucidated by a deductive approach.

Conclusion

This is the first qualitative systematic review and synthesis of the perceptions and experiences that parents of children with ASD have about PMI. The three themes described in this synthesis illuminate facilitators and barriers to the parent-training component of PMI and explain the outcomes of PMI from the perspectives of parents. There are three key findings. Firstly, the positive parent-therapist relationship, use of group-based format, flexibility and easy accessibility of the training are found to be facilitating parents' engagement in parent-training. Secondly, the complex and overwhelming contents of the training, incompatible training schedule for working parents, and the unmet emotional and educational needs provided barrier for parents to engage in parent-training. Thirdly and finally, the positive impact of parent-training may occur in three levels: the increase of knowledge and skills changed parents' perceptions of their child and improved their sense of

well-being, which in turn resulted in the improvement in parent-child relationship. Overall, the information provided in this review is considered to be of value to the practitioners and developers of PMI, especially for those who seek ways to improve parents' engagement in parent-training and increase their satisfaction with PMI.

CHAPTER 5

STUDY 2

A qualitative analysis of parent's perceptions and experiences of ESDM based parent-training and low-intensity direct-ESDM therapy

The present study is a qualitative analysis of interview data collected during the experimental research conducted by Dr Hannah Waddington and her research team. In the course of their research, they interviewed parents about their experiences of participating in parent-training, along with the direct therapy provided for their child. The objective of this study is to analyse the interview data in order to gain an in-depth understanding of parent's experiences of the given interventions. In this respect, it is necessary for the readers to understand the background of the original research and where the data was sourced from. A brief description of the experimental research is provided below.

An overview of the experimental research

The main objective of the experimental research conducted by Dr Waddington and her research team was to evaluate whether ESDM parent-training improves parent use of ESDM techniques and increases children's imitation, expressive language, and joint engagement, as well as to evaluate whether low-intensity direct ESDM therapy following the parent-training leads to additional gains in these child outcomes. Four families of a child with ASD participated. A detailed description of the participating families' characteristics is provided in the method section of this study. Parent-training and direct therapy was delivered in the participating family's home, except one family who attended parent-training and the direct therapy at a community centre.

Dr Waddington's research team employed a multiple-probe-across-participants design which included four phases: baseline, parent-training, post-parent-training baseline, parent-training, post-parent-training/direct-therapy baseline, direct-therapy, and follow-up. At the

beginning of the parent-training and direct-therapy phases, the ESDM curriculum assessment was conducted to determine developmentally appropriate goals for each participating child. The training and the therapy were aimed at supporting the parents and the children to meet the identified goals.

In the ***parent-training*** phase, the parents received one 1-hour long parent-training session for 12 weeks. The format and the contents of the parent-training were based on the ESDM parent manual: *An early start for young children with autism* (Rogers, Dawson, et al., 2012). The parent-training was provided by Dr Waddington who was the first author of the experimental research. Dr Waddington is a registered and certified ESDM therapist and she completed the ESDM parent-coaching training. However, she was not yet a certified ESDM parent-coach. To become a certified ESDM parent-coach, an individual must be a certified therapist and complete a parent-coaching workshop as well as a parent-coaching certification supervision (UC Davis Health, 2020). Dr Waddington is a registered Educational Psychologist.

Once the parent-training was completed, the ***direct-therapy*** phase began, which lasted for 12 weeks. The direct therapy intervention was based on the principles of the ESDM and it was also informed by the therapist manual: *Early Start Denver Model for young children with autism* (Rogers & Dawson, 2010). During this phase, each child received one hour of low-intensity direct ESDM therapy twice a week. This was delivered by the second and third authors of the experimental research who had completed the advanced ESDM training and became certified ESDM therapists shortly after the conclusion of the research. Each therapist worked with two of the participating children and their families During this phase, the parents were encouraged to observe the therapy and were provided with brief therapist-delivered feedback on the session. For research purposes, each therapy session was video recorded to evaluate child outcomes.

In each of the post parent-training and post direct-therapy phases, the parents were invited to two one-hour long semi-structured open-ended interviews. The first interview was conducted one week after the final session of parent-training (post parent-training). In this interview, the parents were asked about their experience the parent-training. The second interview occurred one week after the final session of the direct therapy intervention (post-direct therapy). In this interview, the parents were asked about their perception of the direct-therapy and compared their experience between the parent-training and the direct-therapy. The two therapists who provided the low-intensity direct ESDM therapy interviewed the parents. Each was assigned to the two families with whom they did not provide intervention during the direct-therapy phase, thus the parents were unfamiliar with the interviewer that conducted the interview.

The interviews followed a series of open-ended questions which were prepared in advance. Both interviews began by asking background information about the child and parents such as the child's current interests and the parents' goals for their child. In the post parent-training interview, the interviewers explored the parents' experience of the following topics: *parent-training structure and techniques, ESDM strategies taught in the training, child outcomes,* and *relationship with trainer*. In the post direct-therapy interview, the interviewers explored the parents' experience of the following topics: *structure, parents' involvement in therapy, ESDM strategies, child outcomes,* and *relationships with the therapist*. In this interview, the interviewers also explored parents' preferences between the parent-training and direct therapy phases in relation to *the structure, parent's involvement and outcomes*. The list of questions is included in the Appendix E.

Methodology

Qualitative content analysis

As the goal of this study was to gain an in-depth understanding of parents' perceptions and experiences regarding ESDM-based parent-training, the current study employed qualitative content analysis. Qualitative content analysis is one of the most commonly used methods for analysing text data or recorded communication such as interviews transcripts, protocols of observations, and the like (Hsieh & Shannon, 2005; Mayring, 2004). It uses a systematic process of coding and identifying themes or categories to interpret the text data (Hsieh & Shannon, 2005). It is important to note that qualitative content analysis is different to quantitative content analysis. While quantitative content analysis focusses on quantifying the surface meaning of the text data by counting codes, qualitative content analysis seeks subjective meaning of the text data and focuses on interpreting the patterns found in the codes (Morgan, 1993).

Hsieh and Shannon (2005) identified three distinctive approaches within the application of content analysis in the field of qualitative research: the conventional, directed, and summative content analysis. The use of conventional content analysis was deemed most appropriate for this study as it is most well suited for understanding and "describing [a] phenomenon" (Hsieh & Shannon, 2005, p.1279). In this case, conventional content analysis was invaluable for understanding the perspectives and experiences of the parents who participated in ESDM based parent-training and the low-intensity ESDM direct-therapy.

According to Hsieh and Shannon (2005), conventional content analysis encourages researchers to be absorbed into data without a set of prescribed ideas and to allow the themes or categories to emerge naturally from the data. In turn, it enables researchers to bring out "new insights" from the data (P. 1279). It was considered of particular value to this study as I wished to observe novel and unprecedented aspects of parents' perceptions that are distinct

from the previous similar study conducted by (Waddington, 2018). In her doctoral dissertation, Waddington (2018) provided parent-training based on ESDM to five parents of a child with a diagnosis of ASD and conducted a semi-structured open-ended interview with the parents about their experiences and perceptions of the intervention and training procedures. The interview data in her work was analysed using a deductive thematic analysis informed by the theories of social validity. The conventional content analysis employed in this study interprets data from an inductive perspective. By utilising a data-driven rather than a theory-driven approach, I believe that this study has potential for obtaining new insights about parents' experience of ESDM-based parent-training and adds value to the earlier work of Waddington (2018).

Furthermore, the data Dr Waddington requested to be analysed was qualitative in nature. Upon reviewing the transcripts, I realised that there was more structure to the questioning than would have been ideal in a truly inductive study. Nonetheless, my supervisor and I decided to take an inductive stance to the data in the understanding that many parents would have contributed spontaneous comments which would be missed if the analysis followed the interview structure too closely. Therefore, I paid close attention to any spontaneous or unscripted comments from either the interviewer, or the parents as potentially rich sources of data over and above the comments elicited by the interview questions.

Ethical considerations

The current study was approved by the Chair of the Human Ethics Committee on behalf of the University of Canterbury after reviewing the University of Victoria (Wellington) HDEC application provided by Dr Waddington, who was the primary researcher of the experimental study.

Consideration of the participants' anonymity and confidentiality was considered in the process of obtaining, analysing and reporting the interview data. First, the parents who

participated in the experimental research were informed of my involvement as an external analyst of the interview transcripts. Secondly, it was agreed with Dr Waddington's research team that the verbatim transcription of the audio recording would be completed by them to minimise the possibility of revealing the participants identity. The names of the participating children were also modified prior to being provided for the analysis. Lastly, in reporting the findings of the analysis, the participants' quotes were presented without names or pseudonyms to ensure complete participant confidentiality. It was thought that, in a small community like New Zealand, there was a greater possibility that the identity of the participants could be revealed through reading their comments about their personal lives and experiences in relation to the questions being asked during the interview.

Method

Participants. The participants of the current study were the parents who participated voluntarily in the two one-hour long semi-structured open-ended interviews following the completion of ESDM-based parent-training and low intensity ESDM direct-therapy provided for their child. Of the parents who participated in the interviews, there were three mother and father dyads (parents of Manu, Jeremiah, and Felix) and one mother (mother of Zane). The participants' characteristics are presented in Table 5.1.

Felix's parents were a married couple with two children. Felix is their youngest child, and he was five at the time of their participation. Felix's mother was the primary participant of the parent-training. Only Felix's mother attended in the post parent-training interview, and Felix's father joined in the post direct-therapy and the comparison interview.

Jeremiah's parents were a married couple with have four children. Jeremiah is their youngest child, and he was six years old at the time of their participation. Jeremiah's parents did not have their own home at the beginning of their participation in the research; thus, they received the parent training and the direct therapy at the community centre. Both of

Jeremiah's parents were present for the parent training, but only Jeremiah's father was able to be present consistently during the direct-therapy phase. Both of Jeremiah's parents attended the two interviews. While other parents had not been involved in any autism-specific parent-training prior to engaging in the experimental study, Jeremiah's parents received autism specific parent supports from another agency, which was not considered by the researchers to be parent-training.

Manu's parents were a married couple with two children. Manu is their youngest child, and he was four years old at the time of their participation. Manu's father was the primary participant in the parent-training. Both Manu's mother and father attended the both interviews.

Zane's parents were a married couple, and they have two children. Zane is their eldest child, and he was three years old at the time of their participation. Zane's mother was the primary participant of the parent-training, and she attended both interviews.

Table 5.1

Participating Parents' Characteristics

Participants	Felix's parents	Jeremiah's parents	Manu's parents	Zane's mother
Child (Age)	Felix (5)	Jeremiah (6)	Manu (4)	Zane (3)
Primary participant of parent-training	Mother	Mother	Father	Mother
Employment status of the primary participant	Part-time	Part-time	Stay-at- home	Part-time
Marital status	Married	Married	Married	Married
Education	Postgraduate	High School	Bachelor	Professional qualification
Languages spoken at home	English	English and Samoan	English	English
History of participating in other parent trainings	None	ASD specific parent support	None	None

Data collection. The semi-structured interviews of each participating parent were audio-recorded and transcribed verbatim. The transcription was completed by the research team of Dr Waddington and provided to me for the present study. The transcriptions comprised a post-training, post-therapy and comparison interview transcription for each family. The names of the children were modified to protect their identity.

Data analysis. The specific steps of the analysis were guided by the qualitative content analysis method proposed by Graneheim and Lundman (2004), which was based on the conventional content analysis approach. In the first step of the analysis, I read and re-read each transcript to become immersed in the data. Once I gained a sense of the whole transcript by reading and re-reading, meaning units were identified in all the transcripts. Graneheim and Lundman (2004, p. 106) refers to a meaning unit as "words, sentences or paragraphs containing aspects related to each other through their contents and context." The next step was to condense the meaning units, which is called 'condensation' by Graneheim and Lundman (2004, p. 106). Condensation is a process to reduce or shorten the size of the identified meaning units while "preserving the core" by maintaining the essence of what has been said or expressed in the text. For example, I identified the following sentence as a meaning unit; "*once a week, same time every week, it helps me to structure my day when I am not working.*" It was then condensed into "*regular session helped to structure the day when not working.*" In this process, I shortened the text while preserving the core of what was said by the participant.

The third step was to identify the 'content area' which is referred to as "a text dealing with specific issues" or "parts of the texts that address a specific topic in an interview" (Graneheim & Lundman, 2004, p. 106). As the interview scripts followed the structure of the questionnaires developed by the research team of Dr Waddington, the responses of the participants were categorised into a list of contents such as the child characteristics, the

reason for participation, the location, timing and materials of the parent-training etc. The fourth step involved labelling the condensed meaning units with codes (Graneheim & Lundman, 2004). Codes are thought to emerge from the data itself (Hsieh & Shannon, 2005; Vaismoradi, Jones, Turunen, & Snelgrove, 2016). Graneheim and Lundman (2004) stated that codes are "tools" and "devices" that allow researchers to organise and understand data in "new and different ways" (P. 107). The coding was performed manually using Microsoft-word first. The identified codes were then entered into NVivo, a qualitative data analysis software, and tagged into the relevant sentence or sentences in each transcript to facilitate the analysis. An example of identifying the content area and coding process is presented in Table 5.2.

Table 5.2

An example of identifying content area and coding process

L	Meaning Units	Condensed meaning Units	Content areas & Codes
M	Um, once a week, same time every week, it helps me structure my day when I'm not working. And they come to the house, which is amazing. I mean we don't have to, I don't have to get out of my slippers – [laughs] um as you can see. Um, and you know, that kind of environment just makes it so much more comfortable for everybody. It's not some kind of sterile, you know, room at the hospital, or a lecture room or anything like that. It's your home and you've got all your tools and um, stuff around you that you can just grab and use.	Regular weekly session helped to structure day when not working. Happy with homebased Can be relaxed. More comfortable. Uncomfortable with the sterile environ. Home has everything she needs.	**Time**- positive frequency. **Location**- convenience of home, comfortable at home, uncomfortable with a community centre based location, home has readily available resources.

As the last step, I created categories and developed themes. According to Vaismoradi et al., (2016, p.102), a theme refers to "a more implicit and abstract level, which requires interpretation" while a category is defined as an "explicit content of text" that "is a simple description of the participants' accounts". In this respect, developing themes can be understood at more of an "interpretive level" than the process of coding, and is considered to be a means to reveal "the underlying meanings" by capturing the recurring patterns within the data (Graneheim & Lundman, 2004, p. 107). It is believed that the identified themes will

provide an in-depth understanding of the underlying thoughts, perceptions and values of the participants (Vaismoradi et al., 2016). In order to construct themes, the identified codes were grouped into a set of categories first by comparing them based on their similarities and differences as well as their relevance to the research questions. Additionally, two sets of maps (post parent-training and post direct-therapy) were organised based on the content areas. They were used to identify the recurring theme or connection between codes identified across the content areas. The maps are included in the Appendix D. From this, a set of initial themes were developed. Upon reviewing those themes, they were organised and grouped in relation to their conceptual similarities. In turn, they were named as sub-themes and main themes. An example of the process of theme development is presented in Table 5.3.

Table 5.3

An example of the process of developing themes

Main theme	Facilitators		
Sub-theme	Accommodating parents' needs		
Category	Convenience of home-based setting	Convenience of handouts	Benefits of having extra person
Codes	Happy with home-based training Convenience of home location Comfortable with home environment Reduced stress/pressure on parent Familiar environment for child Readily available resources Easy access to resources Dislikes of sterile environment Applicability of learning at home Difficulty going elsewhere Preferred home based	Happy with handouts Good reminder Handouts were convenient Beneficial for sleep deprived parents	Appreciation of having extra person to care for child

Trustworthiness. Several steps were taken to ensure the trustworthiness of the findings of this study. Trustworthiness refers to the concept of *credibility*, *dependability* and *transferability* (Graneheim & Lundman, 2004). *Credibility* refers to the extent to which the interpretation and representation of the data aligns with what the researcher intended to study

(Cope, 2014). *Dependability* refers to the stability of the data over time, and *transferability* refers to the applicability of the data to other similar contexts (Cope, 2014).

Graneheim and Lundman (2004) claimed that, in order to achieve *credibility,* careful selection of the relevant and appropriate meaning units that are not too long but not too narrow is essential. In order to do so, my thesis supervisor (Karyn France) and I chose to identify meaning units and condensed meaning units independently before coding and comparing with each other. This was considered as a cross-checking process where I checked my understanding of the semantic content of the transcripts that were similar to those of my supervisor. It was considered particularly beneficial in reducing the potential error associated with misinterpreting the contents of the data, given my cultural and social positioning: that is, I am an immigrant to New Zealand and English is my second language.

My thesis supervisor and I independently identified meaning units and underwent the condensation process using one of the post-therapy interview transcripts. Approximately 80% consensus was reached. Any differences were too insignificant to warrant further investigation, and we were able to reach agreements on the differences following a short discussion. An example is provided in the Table 5.4 below, where my supervisor and I condensed the identified a meaning unit in a slightly different manner. I identified that the improved status of the child made a positive impact on family, whereas my supervisor considered that the impact was made from the programme. After a short discussion and reviewing of the meaning unit, the differences were settled, and it was agreed that what the parents expressed in the identified meaning unit indicated that the improvement of the child made a positive impact on the family. The same process was repeated with one comparison interview transcript where my supervisor identified the units of meaning from approximately 25% of the transcription. After 80% consensus was reached, it was agreed that an acceptable reliability was met to begin the initial coding process.

Table 5.4

An example of the comparison

Identified meaning unit		Condensed meaning unit
That's, he is in a good place. And that we're really happy that he's happy, generally pretty happy. You know? And, 'cause that makes a huge difference.	Mine	The child is in a good status and it made a huge impact on family.
	The supervisor	He is happy and they are happy. Programme makes a difference.

The *credibility* of the research findings also concerns the ability to provide evidence to substantiate the analysis, in this case the generation of categories and themes (O'Brien, et al, 2014). To do so, Graneheim and Lundman (2004) suggest seeking agreement among co-researchers, experts and participants. They further stated that, although it may seem unreliable given the highly subjective nature of understanding human experiences, the process of opening up and remaining in "dialogue" with others provided further *credibility* to the steps that researchers took to their discovery (p. 110). The open dialogue can also be seen as an attempt to establish the *dependability* of the study, as it ensured the consistency of my judgements to analyse data and identify themes (Graneheim & Lundman, 2004). Given the nature of master's thesis research, the coding was done mostly by me, but the progress and the outcomes were extensively reviewed and discussed with two of my thesis supervisors. To facilitate the *transferability* of the study findings, I attempted to gather the most suitable and relevant quotes from the participants that were rich in quality. Reviewing the placement of the participants' quotes in relation to the relevant themes, along with my supervisors, further increased the *transferability* of the study findings.

Guidelines for reporting qualitative research proposed by O'Brien, Harris, Beckman, Reed, and Cook (2014) were also used in this analysis. As part of this, *reflexivity* was considered throughout the process of analysing and synthesising data. In qualitative research, it is a well-accepted notion that the researcher is a part of the world he or she intends to study, thus it is impossible to detach the findings of the research from the perspectives of the

researcher who conducted the study (Elliott et al., 1999). Therefore, the role of the researcher in the process and production of the research findings must be analysed as a part of the data. Reflexivity is, simply put, a way of acknowledging this by recognising personal biases that a researcher may have brought to the research process and understanding how these may have interacted and influenced the findings of the research (Dowling, 2006). O'Brien, et al (2014) recommend that providing a description of the researcher's characteristics is one way to make the role of the researcher visible. This way, it reminds both the readers and the researchers to consider the influences that the researcher may have on the process and the findings of the research. A description of myself in relation to this study was provided in the Chapter 3 under the title of 'positioning myself as the researcher'.

Results

The following section presents the findings of the qualitative analysis of the semi-structured interviews conducted with the parents of four children (three mother and father pairs and one mother) who received ESDM-based parent-training and low intensity direct-therapy. Analysis of the post-training interview and the post-therapy interview will be provided separately. Finally, a comparison of parents' experiences with each form of intervention will be provided.

Part A: Post-parent-training interview

As illustrated in Table 5.5, the analysis of the post-training interview revealed four main themes, namely *background factors*, *facilitators*, *perceived barriers*, and *perceived benefits*. Each one was presented with several sub-themes. The first theme, '*background factors*' reflects the prevailing contexts of what parents experienced before participating in parent-training and their overall impression of the training. The second theme, '*facilitators*' covers the elements of parent-training that promoted positive engagement of parents and facilitated their learning. The third theme, '*perceived barriers*' addresses the obstacles or

challenges that parents faced during their participation. The last theme, '*perceived benefits*' describes parents' perspectives of the outcomes of parent-training.

Table 5.5

Theme table

BACKGROUND FACTORS	FACILITATORS	PERCEIVED BARRIERS	PERCEIVED BENEFITS
LACK OF SUPPORTS	ACCOMMODATING PARENTS' NEEDS	SYSTEMATIC AND CONTEXTUAL BARRIERS	BENEFITS OF THE TRAINING ON PARENTS
	TRAINER'S PERSONAL CHARACTERISTIC		
POSITIVE IMPRESSION OF PARENT-TRAINING	DELIVERY OF TRAINING	LACK OF FIT BETWEEN PARENTS' LEARNING STYLE & TRAINING TECHNIQUES	BENEFITS OF THE TRAINING ON CHILDREN
	TRAINER'S RELATIONSHIP WITH PARENTS AND THEIR CHILD		

Theme 1: Background factors. The first theme 'background factors' was comprised of two subthemes; lack of supports and positive impression of parent-training. This theme is of particular value to this analysis as it happened to be based on the comments of parents that were not elicited by the interviewer, but which emerged spontaneously. As I described earlier, my intention to approach the data from an inductive, open-minded and inclusive manner was to gain new insights into parents' experiences that would otherwise remain hidden if I was to restrict my attention to the comments related to questions being asked. Understanding the prior experiences that parents had and how it impacted on their impression about the training was both interesting and a useful source of reference in making sense of what parents of children with ASD want or need.

Table 5.6

Background factors

Sub-themes	*Description*

Lack of supports	▪ Lack of available resources, difficulty accessing appropriate services, and incompatibility of other interventions services to their needs
Positive impression of the training	▪ Expression of a high level of satisfaction in relation to the prior lack of supports

Lack of supports. This subtheme relates to parents' experiences prior to engaging in the training. In the interviews, three parents frequently cited their struggles with lack of supports available for families of children with ASD, and described having experienced a lack of available resources, difficulty accessing appropriate services, and incompatibility between interventions services and their needs. As a result, parents reported a high level of dissatisfaction with other ASD interventions or support services. This is illustrated by the following quotes:

> *"Oh, I mean, I don't know, I am so over therapy in other places…It's just a fucking waste of time."*

> *"Um and the support services* [for children with ASD and their families] *are pretty rubbish. And the funding is rubbish."*

One parent expressed a need for care coordination for families of children with ASD and explained that:

> *"One of the big challenges that I have with all interventions is um, is that you're in this position of trying to pick and mix from the lolly bag and no one is willing to give you any advice and you're picking and mixing from this bag, and that one of the most frustrating things out of all of it… I'm pretty convinced there needs to be a… fundamental change."*

Positive impression of parent-training. Throughout the interviews, all parents, except one, made spontaneous comments (that were not elicited by the interviewer questions) on how satisfied they were with the training when discussing the specific elements of parent-training or procedures. Parents also expressed their appreciation for the opportunity to participate in the research. The high level of satisfaction regarding the training was demonstrated in the follow quote:

"I think that overall, it has just been really awesome... Its stuff that will stick with us now and it is really important stuff that we never thought would be! Like we would never have come up with all this had we not been taught it!"

Reflecting on the previous sub-theme *'lack of supports'*, some parents expressed their satisfaction with the training in relation to their struggles. For example:

"I found that who dealing with um [sic] *dealing with autism early intervention therapists as a whole incredibly frustrating, but it* [ESDM] *has been one of the best things."*

"I've seen first-hand how much of a difference [the training] *can make and yeah… it's really great. And also just seeing what else there is on offer, there's nothing that I've seen that comes even a tenth of the way near it…what the ministry of health and the ministry of education offer is always going to be the cheapest alter- ah option, which is generally inviting a whole load of parents to be spoken at and no practical…"*

In addition, two parents expressed their wish to have the ESDM based parent-training available for other parents of children with ASD in New Zealand:

"I just hope that lots more parents in New Zealand have the opportunity to experience it."

Theme 2: Facilitators. One of the main objectives of this thesis was to gain insight into the elements of the ESDM based parent-training that contributed to the training being a positive experience and an acceptable form of intervention to parents. Several facilitating factors were identified and sub-themed. They are illustrated in Table 5.7.

Table 5.7

Factors that facilitated parents' engagement and satisfaction

Sub-themes	*Description*
Accommodating parents' needs	▪ Providing a convenient location, materials & an extra person to care for child promoted parents' overall satisfaction
Trainer's personal characteristics	▪ Being non-judgemental, passionate & having knowledge and experience of working with children with ASD

Delivery of training	▪ The flexibility in training process, parent-led approach, provision of positive feedback & the use of simpler terms
The trainer's relationship with parents and their child	▪ Comfortable & positive relationship with the trainer is critical ▪ Importance of trainer's positive interact with their child ▪ Trainer to interact with the child is beneficial as it helps trainer to understand what parents are going through

Accommodating parents' needs. Supporting and accommodating parent's needs by providing a convenient location, materials and an extra person to care for the child promoted parents' overall satisfaction with parent-training. All parents who received the home-based training reported that the convenience of home-based training was highly beneficial for their family circumstance. They all described the location as "*amazing*", "*perfect*", "*helpful*", and "*awesome*". Among those parents, the convenience, relevance and easy accessibility to relevant resources at home were identified as the main advantages:

> *"It's your home and you've got all your tools and um, stuff around you that you can just grab and use."*

> *"… the only environment that* [my child] *is actually comfortable is our home, so it was really awesome to have* [the trainer] *able to come here, like. And you know, get some tips for what works in our setting because that's where we are."*

> *"[I]t was helpful because if* [another child] *needed to sleep he could be in his cot, or bed. You know, so what was good."*

On the contrary, the parents who received the training in a community centre due to the unavailability of their home at the time of the programme, expressed that they "*would have preferred*" the home-based setting, and identified the initial difficulty associated with attending parent-training in the community centre:

> *"Yeah, the first time we came… It was a bit of a struggle… Trying to settle him down, because he does not want to be here."*

Parents expressed a high level of satisfaction with the convenience of handouts that summarised the core concepts, techniques, and strategies. In particular, some parents

highlighted the functionality and usability of the handouts and expressed how it met their learning needs:

> *"*[T]*he handouts are a good reminder, because you can easily forget what you have learnt here."*

> *"*[T]*hey* [the handouts] *were brilliant. We had them up on the board there and used to just check it."*

The convenience of the handouts appeared to have increased the likelihood of parents practicing the learnt techniques and strategies. One parent highlighted the poor quality of sleep experienced by many parents of children with ASD, and addressed the value of the handouts in enabling them to practice implementing strategies quickly and easily when they had time:

> *"…if you go to a course elsewhere and then you've got all this reading and things like that, you know it's quite hard when you are really sleep deprived to translate that into practice whereas it's much easier if you have* [the handouts], *have already done it once in the home. Then it is easier to do it again."*

One mother also mentioned the benefits of being provided with an extra person to care for her child during the training, and explained how it accommodated and supported her learning:

> *"*[T]*he other thing I liked was that she also brings someone along so they can play with* [child] *while you're actually trying to talk, because that's a really… like today, it's okay, but sometimes it's quite hard work."*

Trainer's personal characteristics. Parents identified a set of personal characteristics that promoted positive engagement with the trainer. These included being non-judgemental, empathetic, patient, friendly, understanding and passionate. A non-judgemental attitude was particularly valued given the parental experience of social stigma associated with autism and the location of the training – that is, having to accommodate the trainer in their own house:

> *"Non-judgemental is probably the, one of the key things… 'cause I guess when you have a kid who is autistic, you're always getting judged by other parents* [laughs]*."*

> *"I certainly didn't feel you know, awkward or anything around her. I was quite happy to be myself."*

The trainer's passion for her work was another personal trait that the parents valued strongly. One parent described the trainer as being *"*[h]*ere for the right reason*" and appreciated the trainer's passion. Another parent stated that:

> "*…you can actually tell when somebody is actually invested in what they are doing. And I see that through* [the trainer]*."*

The trainer's expertise and experience in working with children with ASD were also acknowledged and valued by the parents. For instance, parents said that "[I] *got the feeling that she could understand* [my child] *a bit*" and "*she's great, a great* [trainer]*, and um very experienced, clearly*."

Delivery of training. This sub-theme captured the elements of training techniques and approaches that parents identified as beneficial. These included flexibility in the training process, a parent-led approach, provision of positive feedback and the use of simpler terms. First of all, parents frequently acknowledged and valued the trainer's ability to read and respond appropriately to meet parents' learning needs:

> *"*[T]*he thing that I really liked was the* [trainer's] *ability to adapt if things weren't working."*

> *"She read us really well. She knew when there were days when we had had a hard day, she would read us really well, actually. And the fact that she wouldn't just bombard us with a whole lot of new stuff if she knew that we weren't, if I wasn't fully 100%, or* [my child] *wasn't, she would always ask us first whether we wanted to continue learning this technique, or what we did last week, that kind of stuff."*

In doing so, it was identified that the trainer consistently sought to understand the needs and wants of parents. The trainer was perceived to be open and responsive to parents' suggestions as well. This parent-led training approach was acknowledged and appreciated. One parent stated that the trainer asked constantly "*what* [the parent's] *preferences were, what* [the parent*] wanted to do as well.*" Other parents said the trainer "*was really good at giving us the opportunity to lead*" as she often asked parents opinions about the way she could deliver the training.

In relation to the parent-led approach, the non-instructive training approach and goal-setting process that encouraged parents to identify their own agendas were identified as positive elements in the training process. For instance, one parent said that, in order to learn, parents "*need to tell themselves what to do*" rather than being told by others in order to learn.

Provision of positive feedback was identified as a positive aspect of the trainer that created a supportive learning environment.

> "… focusing *on the good stuff, um yeah, and I think* [the trainer] *does that really well. Yeah, focusses on what has worked, um you know, rather than what was a challenge."*
> *"if you are feeling good about it, you're much more likely to use the techniques that are…*[r]*ather than feeling guilty because you're not doing it right, or, yeah."*

Lastly, the use of simple terms when providing training was identified as beneficial:

> *"…Using simple terms that can actually relate to people, and it think that that was what was good about* [the trainer] *... She never made something look so complicated... There are some people that you just don't get because of the terms, and it is so easy to get lost in all the terminology…"*

The trainer's relationship with parents and their child. All parents, except one mother, reported that their relationship with the trainer was important and positive. Although the mother described her relationship with the trainer in a positive manner, she stated that the

relationship was not an important factor in her training experience. However, she indicated that feeling comfortable with the trainer may increase the likelihood of parents to ask more questions. Similarly, one parent emphasised the importance of having "*the right person*" as it may facilitate parents' learning and their likelihood of implementing the leant strategies:

> *"…if you lose respect, you're not really going to listen to what they say… So I think it is pretty important to have the right person."*

Another parent mentioned feeling "*vulnerable*" about being in the training process, such as being coached or videoed, and emphasised the importance of the relationship with the trainer.

All parents reported that the relationship between the trainer and their child was positive in general. In particular, one parent acknowledged the effort that the trainer made to get to know the child. Another parent also mentioned that she felt as if the coach cared about her child and how it contributed to her relationship with the trainer:

> *"I genuinely feel from her, well the vibe I get from her is that she does care about* [my child], *and because of that my respect for her is high. Oh no, I am getting emotional."*

Moreover, it appeared that the interaction between the trainer and their child was perceived to be of a particular value to the parents:

> *"It was really important because we were learning with her, and you can't learn something of someone if they are not preaching it themselves... you know, it is that thing aye, you practice what you preach, so…"*

> *"And* [the trainer] *um, can also feel how it is like to try and engage [my child]and things like that because … if she herself has that time to do that then she can kind of tease what are the easy things with* [my child], *and what are the difficult things."*

Theme 3: Perceived barriers. Another objective of the thesis was to identify the factors that challenged parents' engagement in parent-training. Two main factors were

identified and sub-themed as follows; systematic and contextual barriers and lack of fit between parents' learning style and training techniques.

Table 5.8

Barriers that challenged parents' engagement to parent-training

Sub-themes	*Description*
Systematic and contextual barriers	▪ complexity of training contents in the latter part, challenging life circumstances and use of manuals
Lack of fit between parents' learning style and training techniques	▪ preference of expert inputs rather than personal reflection ▪ preferences of using visual materials in training process

Systematic and contextual barriers. Parents identified several contextual barriers that contributed to their difficulties keeping up with training; the complexity of the training content, challenging life circumstances and use of manuals. One mother reported that the increased complexity of contents in the latter part of training was challenging for her and expressed a need for more sessions towards the end. She said:

> *"Just to kind of, because it's in that second half of the twelve weeks that things really ramp up and that actually really having to think and practice quite hard… Ah, so yeah, possibly twice a week at the end could maybe back up some of the things."*

On the contrary, one mother reported that having the training once a week was *"a little bit too soon"* and she preferred fortnightly training opportunities. She identified her challenges with managing multiple demands such as personal, work and family commitments and reported difficulty finding time to practice.

> *"I felt that um, I felt that life for me is just a little bit hectic. Cause, its busy, I think just. I don't know, with 2 young kids and when you are attending* [another intervention service]*, a then um, even just trying to get him to kindergarten. You know, I just felt there was heaps and then you have got work on top of it and trying to keep your house clean. I just thought that man there's just heaps going on."*

She also questioned the suitability of the training and described it like this:

"I guess it just maybe wasn't the right timing for me in terms of. But maybe like it's always going to be like that."

Using manuals was reported to be challenging as well. One mother reported dissatisfaction with manuals due to the overly technical terms and descriptions:

"I just probably wouldn't bother giving that to parents I think it's too much hard. I mean, they have got enough on their plates. I don't think it was very well written."

The American terms used in the manuals were reported to be challenging as well. One mother cited the unsuitability of the use of American phrases in the New Zealand context. Interestingly, she emphasised the importance of adaptability and shared her strategies to overcome the challenge:

"I think being able to, you've got to be able to put it into your own language. Otherwise it doesn't feel um, as natural."

" just about, you've got to put, you've got to put these situations, you've got to give your lens, your family lens ah put the lens on all of that stuff."

Lack of fit between parents' learning style and training techniques. A lack of fit between parents' individual learning styles and the training techniques was identified as a challenging factor for some parents. One mother, in particular, felt that reflecting on her own practice was unhelpful and expressed that she preferred to have more input from the trainer. She said:

"I found that the reflection from me,...I wouldn't use the word confronting, but, you know like, you're trying to learn something so really, I don't think that it matters to much what I think I'm doing, like I probably just wanted to hear what [the trainer had to reflect]… "

Interestingly, another parent identified the reflecting technique as a positive training technique as it fitted her learning style:

"Yeah, it's like any, any learning. You know, you've gotta go over what you did, and practice it to make sure you've got it."

One mother, referred to herself as "*more of a visual learner*" and suggested that the use of video footage of herself may have helped her to reflect better than just talking about it with the trainer. She also suggested that the use of visual materials in the training process could be more beneficial:

"I probably would have learnt more if would have seen a video from [the trainer] showing the techniques with may be another child"

Theme 4: Perceived benefits. The final theme explored parents' perspectives on the benefits of parent-training for themselves as well as for their child. Two main factors were identified and sub-themed as follows; *contextual barriers* and *lack of fit between parents' learning style and training techniques*.

Table 5.9

Perceived benefits of parent-training

Sub-themes	*Description*
Benefits of the training on parents	▪ Acquisition of new skills and knowledge, and improved understanding of and relationship their child, better family life
Benefits of the training on children	▪ Improved communication skills and social engagement, reduced level of stress and behavioural difficulties

Benefits of the training on parents. All parents reported positive learning outcomes from participating in parent-training, including acquisition of new skills and knowledge, and an improved understanding of and relationship with their child.

All parents reported that the training provided them with "*a lot of skills*" to better interact with their child and manage their behaviours, such as using '*bring it up to their face'* or '*spot-light*' techniques to obtain attention from their child or using '*following through'* or '*controlling resources'* strategies to manage their child behaviours. Some parents reported that learning about those skills helped them to improve their child's "*motivation*" to engage in

learning activities. One mother said it helped her to become more "*conscious*" and "*aware*" of the way she interacts with her child.

One mother reported that the training "*made a massive difference*" as she learnt more about behavioural management. For instance, she accounted the value of learning about the concept of "*rewarding.*" She said it helped her to become reflective of the context of her child's behaviours, which enabled her to respond to her child more appropriately. She also identified the value of the "*child-led approach*" and said:

> "*being led by him is definitely the way to it, and reading him, and sort of getting, and obviously reading what he doesn't want to do."*

Parent-training was reported to have helped parents to understand, communicate and interact with their child better. For example, one mother said, "*because we have learnt how to include ourselves in his play, it has meant a lot more for us to be able to play with him."* She also commented on the positive impact it had made on her relationship with her son and their family:

> *"And I think it has helped us with our relationship with [my child] and it has really helped our family too, to be able to go to normal places and not have to worry as there are techniques for helping him and not having meltdowns all over the place."*

Benefits of the training on children. Parents endorsed a number of benefits associated with parent-training for their child, including improved communication skills and social engagement, reduced level of stress and behavioural difficulties. This is demonstrated in the following quotes:

> *"*[H]*is overall level of engagement is a lot higher than 12 weeks ago. Um, his language is a bit better. I've seen that is certainly more often, is appropriate. Um, he is in a much better place in terms of his stress levels."*

"[H]*e's, less anxious, less um whingy... language is developing … better able to manage everyday life…Probably better behavioural management, better sensory regulation, um, not shouting anymore."*

"I am just amazed at how much he is more verbal now than he used to be. And I know he can understand things, and I can see it, and um, yeah. Just the progress that he has made compared to what it was when he first started."

Part B: Post-direct-therapy interview

Analysis of the post-therapy interview revealed seven major themes in relation to *the home-based setting, relationship with the therapist, impression of the therapist, challenges with the therapy structure, difficulty observing therapy sessions, the therapist's feedback and the outcomes of the therapy*. These themes captured both satisfactory and challenging aspects of the direct therapy perceived by the parents and their suggestions for improvement. The themes and sub-themes emerged from the analysis are described in Table 5.10.

Table 5.10

Theme table

Major themes and sub-themes	
Theme 1.	**Home based setting:** "*Home is where he feels most comfortable"*
Theme 2.	**Relationship with the therapist:** *"You are entrusting someone with your child"* Sub-theme1. Parent-therapist relationship Sub-theme 2. Child-therapist relationship
Theme 3.	**Impression about the therapist:** "*She's going to be amazing with lots of other families"*
Theme 4.	**Challenges with the therapy structure:** *"The therapy was very structured"* Sub-theme 1. Rigidity in the structure and delivery of the therapy Sub-theme 2. Need for more flexibility
Theme 5.	**Difficulty observing therapy sessions:** "*I just looked away not watching the session at all***"**
Theme 6.	**The therapist's feedback:** *"So we can be on the same page"*
Theme 7.	**Outcomes of the therapy:** *"It certainly feels helpful for us"* Sub-theme 1. Child-related outcomes Sub-theme 2. Parents-related outcomes

Theme 1. Home-based setting: "*Home is where he feels most comfortable*". Similar to the responses regarding parent-training, all of the parents who received therapy for their

child at home described their experience as positive and highly satisfactory. The reported satisfaction was strongly associated with the familiarity of the home environment for their child:

> *"It's* [his] *home environment, it's where he um probably feels most comfortable."*
>
> *"*[F]*or us, like we wouldn't have done it* [the therapy] *probably if it hadn't been at home… he could never be in the space to learn anything outside of our home really. Just too stressed."*

The convenience and easy access of available resources at home were also noted:

> *"*[W]*e have everything we need for all our little um, you know, play based interactions and whether that's a social based interaction or an object based interaction, everything's here. So it's, yeah, perfect."*

Parents also reported small challenges with the home-based therapy. One mother noted that her child was less likely to play with objects at home in general, and for that, she found it difficult to engage him in object play. Other parents said they had to put away books that their child liked to read at home, and he began *"to associate* [the therapist]*'s visit with not having books and then gets upset"*. However, the challenges were perceived as minor and did not appear to affect their overall positive impression about the home as a therapy setting. This point was illustrated in the following statement:

> *"I suppose that was probably the disadvantage* [of home-based setting] *but by far outweighed by the advantages of having it here."*

The parents of the child who received therapy in a community centre spoke about their struggles relating to their difficulty traveling twice a week for therapy. They commented that it was not only challenging for them but also for their child:

> *"He has just been crying and crying the last few sessions, and that's where I felt like maybe it was a bit too much? For* [my child] *it was just a bit overwhelming to be coming twice."*

The parents said: "*if it was at home it would be not much of an inconvenience"* and expressed that they would have preferred having two-hour long therapy once a week instead. They also reported that the community centre room was not well ventilated nor child-friendly and it might have contributed to their child's dislike of attending therapy, at times.

Theme 2. Relationship with the therapist: *"You are entrusting someone with your child".* The therapist's relationship with parents and the child was identified as an important aspect of the successful delivery of the therapy.

Sub-theme 1. Parent-therapist relationships. Formation of a good parent-therapist relationship was identified as important to all parents. For example, one mother said "*I think it's pointless if you didn't have a good relationship because then there'd be no communication, and then it's like, it's just a whole heap of wasted time."* Similarly, another parent noted the importance of a good parent-therapist relationship and said that "*having someone around who cares about your child, does goal setting with you, and helping you and stuff, um feels pretty good as a parent*." Others also said:

> *"There's nothing else out there that you know, no one else knows our child better. Other than kindy, so actually, if you put that in perspective it's pretty powerful."*

All parents described their relationship with the therapist as positive in general, and appreciated the therapist's ability to build an easy rapport with them by being caring, non-judgemental and communicating openly. These are illustrated in the following quotes:

> *"It was really nice to be able to sort of have a nice easy rapport when [the therapist] came in, and just chat about what was happening in the day, or what had happened the night before, or had we got no sleep and we were just exhausted."*

> *"[S]he is always very professional but always very caring and interested to hear, you know, how things are with the family."*

Sub-theme 2. Child-therapist relationships. Parents regarded the child-therapist relationship as highly valuable, and perceived it as a key to the therapeutic success:

> *"I don't think the therapy would work if they didn't have some kind of rapport with the child."*
>
> *"*[L]*earning-wise ... being able to learn stuff from [the therapist], he needs to have, to be able to trust her… I think it's important for them to have a good relationship, so that they communicate better. Also, he'll be happy and be able to enjoy being here, rather than not."*

Although one parent agreed on the value of a good child-therapist relationship, he emphasised the importance of taking a realistic approach, given the frequency of contact his child had with the therapist. He also commented that the goal of the therapist was not about building "*a smooth and easy*" relationship with the child, but to "*teach*" within the given structure.

When parents were asked about their child's relationship with the therapist, parents provided varying views of the relationship ranging from negative to highly positive. Some parents reported that their child's relationship with the therapist was "*not a good relationship*":

> *"Most of the time in the session it wasn't a good relationship. Every time, I could tell when I watch the session he doesn't want to play with her."*

The parents identified several factors that may have attributed to their child's struggles, such as the community centre-based therapy setting, the intensity of the therapy and a dislike of having toys away when learning about sharing.

Other parents described their child's relationship with the therapist as being as "*good as you could expect*" but described some difficulties towards the end where their child became upset with the therapist visits. They explained that their child associated the therapist visit with his books being taken away from him.

One mother said the therapist and her child "*had a pretty good gig going on*" and describe how her child always greeted and farewelled the therapist. Another mother reported that her child was greatly fond of the therapist and described how motivated he was to attend the therapy sessions. She said:

> *"*[My child] *never cleaned up the front room before, but he did when he found out* [the therapist] *was coming"*

Theme 3. Impression about the therapist: *"She's going to be amazing with lots of other families".* Parents reported that an effective therapist must have a good understanding of the children with varying needs and an ability to build a rapport with them. To do so, the therapist must be attuned to children and their family. Knowledge, experience, empathy, authenticity, enthusiasm and transparency were also identified as key attributes of an effective therapist. All parents reported that their therapist had all of the attributes that they identified as an effective therapist and spoke highly of her. The following quotes illustrate this:

> *"… I think* [the therapist] *was amazing and she obviously has worked a lot of different kids with a lot of different needs for a long time and you can see that shining through."*

> *"…connecting with an autistic kid… um you need to bring a lot of vitality, and energy.* [The therapist] *certainly has that in spades, which is really great. And we, you can tell that, I can sometimes bring that, but sometimes you can't, you know? But yeah, she brings it. All the time, and I think that's another one of her really good qualities."*

Parents were appreciative of the flexibility in scheduling that the therapist offered during the direct therapy phase:

> *"She'd let us tell her what would be the best time for us and she'd work around us."*

> *"… she was super flexible which really helped I mean it is quite a long period of time to, to be sort of,* [participate in the programme]*."*

Theme 4. Challenges with the therapy structure: "*The therapy was very structured".* Parents identified the rigid structure of therapy as a challenging aspect of the direct therapy and reported a need for more flexibility.

Sub-theme 1. Rigidity in the structure and delivery of the therapy. Parents frequently cited their challenges with the rigidity in the structure and the delivery of the therapy. One mother spoke about her challenges with the way the therapy was delivered as follows:

> *"… the therapy was very structured, like she had to do these particular things. So there's wasn't actually a lot of room, I don't think, for trying new or different."*

As a result, parents felt the therapist had difficulty accommodating the child's needs adequately or appropriately. For example, one mother noted that:

> *"*[S]*ometimes I felt like some of the sessions were a bit rushed. Because ... We'd come here, he's not settled, and then he's just expected to sit down and play and engage, but he's still upset, you know."*

Sub-theme 2. Need for more flexibility. Parents voiced a need for more flexibility in the delivery of the therapy. Some parents emphasised that the therapist needs to be able to "*read*" the child and willing to adjust the therapeutic approach according to the child's needs. Others suggested that incorporating morning tea breaks into sessions, depending on the child's mood or needs of the day. One mother suggested providing breaks between activities and said:

> *"… sometimes he just got a little bit over, overloaded um. I don't think that was* [the therapist],*I just think it's the way it's delivered um, for that section of the therapy… so possibly just a little bit more space, either in between, or during* [the activities]*."*

In addition, some parents spoke about the challenges of using the same room inside the house to record their child in the beginning of the therapy session and wished for more flexibility. They said:

> *"… I think actually, um, because of the video and stuff, like there are times where he would have responded quite well to running outside and being on the trampoline for example, but, um, because we had to do that first bit inside, yeah it was a bit…*[rigid]."

Theme 5. Difficulty observing therapy session: *"I just looked away not watching the session at all".* All parents identified a number of benefits associated with observing how the therapist delivered intervention to their child including, *learning new techniques from therapist*, *reminding and expanding of the learnt techniques from parent-training*, as well as *affirming the value of consistent use of the learnt techniques*. However, they reported that observing the therapy sessions was challenging. Some parents reported that they observed hardly any sessions. While others reported that, although they were able to observe to some degree, they also found it challenging and "*awkward*".

While one mother reported her difficulty observing due to the caring of the younger sibling, other families identified that difficulty disengaging from their child was the most challenging aspect of the observation. For example:

> *"…I just look away, not watching the session at all."*
>
> *"…It's really hard kind of not to interact [and just observe], because you're so used to trying to interact. And, and of course he, I don't think he really understands why is mum just sitting there and pushing me away, and turning me around to face somebody else when actually I just wanna, you know, do this or that. Yeah so I think, that's, that's the hardest thing."*
>
> *"I found that when I was watching often I got sort of pulled into….pulled in in some way, and I just found it a bit awkward. So I was downstairs, or sitting in our room..."*

Parents identified the ambiguity of their involvement in the therapy as another challenging aspect of the observation. One mother spoke about how difficult it was to just observe without being involved in the therapy. She said:

> *"I think the hard thing for a parent is um, because you know your child best, you know when something's not working or perhaps a way that it could be done better, or differently. And it's really hard not to go, hey why don't you just do 'that' because it interrupts the flow and as part of this therapy, or part of the research. The option isn't really there to go 'hey, why don't we try it this why, or why don't we try it that way?"*

Some parents identified a need for a clear explanation of what parents were supposed to observe or learn. For example, one mother described that *"*[s]*ometimes we just sit there and watch her do therapy, and we're trying to figure out what it is she's actually, what the object is of what she's doing?"* She suggested that:

> *"Maybe just talking through what um like, what they're doing, or what she's* [the therapist] *doing so we can better understand what it is we're supposed to be watching sometimes…Or give us a heads up before it starts,…, like this is the object of what I'm trying to do."*

Some parents suggested that providing a video recording of the therapy sessions may be helpful. One mother, in particular, reported that recording her own practice and comparing it with the therapist's practice would have been more beneficial. She said:

> *"Well I actually personally would have found it more helpful, like as part of the parent coaching to… because… you get all these videos, to … go back and watch it and go 'here you could have done this' and actually then seeing it, … then had an example of someone else who has had a bit more training and that."*

Theme 6. The therapist's feedback: "*So we can be on the same page*". All parents identified the value of receiving feedback from the therapist about their child's progress during therapy. Some parents addressed the importance of being "*on the same page*" with the therapist and described how the therapist's feedback enabled them to do so. They said:

> *"I think there were sometimes, there was one time I thought the session had gone wrong but she was like nah it was actually good because he did this and this and that. And I'm like oh okay. Yeah you're right, he did do that."*

Constructive and balanced feedback was identified as particularly helpful. For instance, some parents described that their therapist was "*good with telling* [them] *straight up if it was a good session or not*" and reported that it was really helpful. Some parents, on the other hand, reported that their therapist was focused mostly on the positive aspect of the child's progress and they preferred having "*a bit more of a reality check*" by learning about what didn't go well with their child.

While one mother acknowledged the value of receiving constructive and balanced feedback from the therapist, she also indicated a need for a collaborative discussion between the therapist and parents in the feedback process. She said that by discussing and working out *"some ideas of what could be better, or what we could try next time"* with the therapist, she "*could practice to try and prepare for the sessions…* [s]*o you've still got someone doing the things at home in between the sessions."*

Theme 7. Outcomes of the therapy: "*It certainly feels helpful for us*".

Sub-theme 1. Child-related outcomes. Child-related outcomes were varied, and a few were common to all families. Some parents had difficulty identifying the impacts of therapy on their child. One parent reported that his child's social engagement with other people had improved but stated that it was "*had to know what has helped him*" or "*how much to attribute*" to the effect of having the therapy. He explained that he shared the ESDM parent-training materials with his child's kindergarten teacher, and the teacher had been using some of the ESDM techniques with him during the therapy phase. He also said that his child's ability "*fluctuates"*, thus it was difficult for him to identify any specific improvements. One mother was unable to observe the therapy. Therefore, it was difficult for her to make a clear link between the therapy and her child's improvement. She reported that her child became more likely to imitate and sing with her. However, she said "*I have been working on it separately, so I don't know if it is ESDM."*

On the contrary, other parents reported that the therapy made "*differences*" to their child. They identified a clear improvement in their child's ability to communicate. One mother said her child is now "*able to tell us exactly what it is that he wants"* by using skills such as "*pointing*" or saying "*help.*" The improvement in communication resulted in her child experiencing "*less meltdowns*" at home.

Another parent reported her child became better at making eye-contact, imitating others and using verbal language. She also noted that her child became more aware of social interactions and began to engage in them with others. She said:

> *"Especially at kindy, new teachers who come in say 'wow, I'm really surprised how good* [my child's] *eye contact is.' Because obviously they've worked with other kids before who perhaps haven't shown that. So I think that's been a huge success"*

The parents strongly attributed the identified improvements to the effect of therapy. One mother said, "*I say it's all, I have strong belief that a lot of it is because of the therapy sessions we've been having with him*." Another mother said, "*I'm pretty sure that um, the programme has given us skills and strategies, and also given* [my child the] *skills and strategies, to be able to navigate through life a little bit easier*."

Sub-theme 2. Parent-related outcomes. Only two parents endorsed the positive effect of the direct therapy on parents. One mother reported the acquisition of skills and strategies to work with her child at home and described it as having "*a little bag of tricks*" or "*a little tool bag*." She also reported having a better understanding of her child and his behaviours, and an ability to respond to him appropriately.

Similarly, another mother described how valuable it was to observe and learn from how the therapist engaged with her child. She said:

> *"I know that* [the therapist] *was testing* [my child] *a lot in regards with what he could take and what he couldn't. It's also taught me that I can do that too."*

Moreover, some parents reported that their relationship with their child had improved as a result of the therapy. One mother described that:

> *"... the biggest thing I think is just being able to um, I don't know, we have a really really close relationship and just the fact that he can understand us, and we can understand him, like he knows when we're not happy, and we know when he's not happy. And um, yeah I think, I see huge improvements in him."*

In addition, she emphasised the importance of "*trusting the process*" and "*being consistent*" in using the techniques and strategies she learnt.

Part C: Comparison interview

Two key themes emerged from the comparison interviews where parents were asked to compare and indicate their preferences between the parent-training and the direct therapy.

Theme 1. Impact of parent-training vs direct therapy. When parents were asked to compare the impact of the parent-training and the direct therapy on their child, differing perspectives were described by parents. Such differences appeared to be related to how parents perceived the use of the ESDM techniques between the therapist and parents' themselves.

Some parents reported that their use of the ESDM techniques at home with their child "*made more of a difference*" in comparison to the direct therapy and emphasised the value of consistent implementation of the ESDM techniques by parents. One father said:

> *"You know, 15, 20 hours per week. I think um, yeah. The gains that we have made have been through that consistent repetition over quite a big chunk of time. And see I'd probably tend to feel that the time* [the therapist] *had available probably not really able to get the repetition, um to really achieve."*

They acknowledged that the therapists used the ESDM technique with "*higher intensity*" but reported no preferences or differences between their use of the techniques to the therapist's. Indeed, one father said "*watching [the therapist] quite reassuring in what I was doing.*"

Although one mother acknowledged that the therapist had "*more advanced knowledge and skills*" compared to her, she identified that her child "*learned more*" during the parent-training phase. Interestingly, she viewed that her child's improvements were a result of "*a combined effort*" between the parents and the therapist. She explained that:

> *"… because without parent intervention you're not going to get anywhere, and without it being, without one on one work with* [my child] *it's not going to be um, backed up. Um. As much, or as powerfully."*

On the contrary, some parents reported that they preferred the way the therapist used the ESDM techniques and indicated that the therapist made more impact on their child. For example, one mother said, "*I think her one is better…*[because] *I'm still learning and she knows more about … the ESDM than I do*." She viewed the impact of parent implementation of the ESDM techniques as secondary to the therapist's, and said, "*I think [the therapist] had more [impact], and like me just following through with it at home which has been a bonus*."

Another mother described the therapist use of the ESDM techniques as "*more cognisant*" and reported that the impact that she made on her child was "*far less than the therapist."* She said:

> *"Well, you're getting way better results with a trained therapist than what you are with a parent. Because as a parent you have got so many different, your mind on. You're really just trying to keep your head above water. Yeah, of course there is going to be way better results for someone who is totally removed from the situation."*

Theme 2. Parents' preference of parent-training over the direct therapy. All parents, except one mother, indicated that they preferred parent-training to direct-therapy. The reason for their choice was strongly associated with the value of parent involvement and empowerment. For example, one mother acknowledged the value of parent-training that facilitated parent involvement and said that "*I think the holistic piece is a lot more powerful because … when everyone's involved I think there's gonna be a better outcome*." Another

mother highlighted the value of parent-training on empowerment of parents and said she would choose the parent training over the direct therapy. She said:

> *"Because we learned a lot more. I learned a lot more in the [parent-training]. Um, and the stuff that's stuck with me now I think it's important for us to know how we can help him."*

Some parents indicated parent-training to be "*a lot more beneficial*" in the long run. They identified the advantage of consistency and longevity regarding the parent implemented intervention compared to direct therapy. One mother said, "*we just have more hours to give to him, and now we know*."

On the contrary, one mother indicated that she preferred direct therapy over parent-training. It appeared that her preference for direct therapy was closely associated with the value of the therapist's expertise which she discussed in relation to the impact of the direct therapy on her child. She indicated that the therapist made more impact on her child through direct therapy and commented that *"well obviously you want the best for your child, so you want [the intervention] with the therapist because they are going to get more*."

Interestingly, she also reported that she would make more effort to read manuals and observe the therapy session if parent-training had not been provided for her along with the direct therapy. This may have been a reflection of her belief about the importance of parent involvement. In response to her preference of parent-involvement between the parent-training and the direct therapy, she said "*you need to learn them yourself because you're not always going to have access to therapy*" and acknowledged the value of the parent-training as follow:

> *"I'm just saying that because the therapy is not going to be available to everybody. Some people won't be able to afford it and things like that so, the parent [training] at least gives you an understanding of … how you could do some things differently."*

Discussion

This study used secondary data collected by the research team of D Waddington to explore parents' perceptions of ESDM-based parent-training and low-intensity direct ESDM therapy. The data was gathered via semi-structured interviews and analysed using an inductive frame, to the extent possible. A content analysis was employed in this study to analyse the data. There were three primary objectives of this study: to uncover parents' perception of (1) ESDM-based parent-training, (2) low-intensity ESDM direct-therapy, and (3) to explore how parents compare their experiences between the two interventions. This study is composed of three parts to address each of the three objectives: *Part A: Post-parent-training interview, Part B: Post-direct-therapy interview, and Part C: Comparison interview*.

Summary of the findings

Part A: Post-parent-training. Four major themes with several subthemes emerged that captured parents' perceptions of the training. The four themes were *background factors, facilitators, perceived barriers* and *perceived outcomes*. The theme *background factors* indicated that parents were highly satisfied with ESDM-based parent-training. Interestingly, parents often endorsed their satisfaction with the training in relation to their prior negative experiences with other services. This finding indicated that, prior to participating in the training, parents experienced difficulties associated with the lack of available resources and struggled to access appropriate intervention services for their child.

The theme *facilitators* captured the aspect of ESDM-based parent-training that promoted parents' satisfaction with the training. These included systematic factors (home-based training set-up and child-care during training), process factors (flexible and parent-led training approach, use of positive feedback and simpler everyday terms), therapist factors (therapist personal attributes such as being non-judgemental and passionate, clinical skills

and knowledge), and relationship factors (positive parent-therapist relationship and child-therapist relationship).

The theme *perceived barriers* illustrated the factors which challenged parents' engagement and learning in the training. These included systematic and contextual barriers such as the complexity of training content, difficulty using manuals, busy personal/family life, and the lack of fit between personal learning styles and the therapist's training techniques.

The theme *perceived outcomes* described the benefits of training parents identified in relation to parents themselves and their child. Acquisition of new knowledge and skills were identified as the main benefits of the training. Parents reported that they could understand and interact with their child better, which improved the relationship with their child. In terms of child-related outcomes, parents reported gains in the areas of communication, social engagement and decreased levels of stress and behavioural difficulties.

Part B: Post-direct therapy. Seven themes were identified that corresponded to both satisfactory or unsatisfactory aspects of the therapy and the outcomes reported by parents. In relation to satisfactory aspects of the therapy, parents identified a number of factors which included a home-based therapy setting, a positive parent-therapist relationship, a positive child-therapist relationship, positive personal attributes of the therapist, flexibility in scheduling, and constructive feedback. In terms of the unsatisfactory aspects of the therapy, parents identified the use of overly positive feedback and the rigidity in the structure and delivery of the therapy. Parents who attended a community centre for the therapy reported that attending therapy twice a week was challenging. Parents also identified a particular difficulty observing the therapy session.

In terms of the outcomes of the therapy, parents offered varying perspectives. All families reported a positive change in their child's communication skills and social

engagement to varying degrees. Two families reported that they were unable to confirm that the change was the result of the therapy as their child received interventions outside the direct-therapy hours which included parents' use of the ESDM techniques with their child. Furthermore, only two families reported a positive effect of observing the direct therapy. The two families reported that their knowledge and skills of the ESDM techniques improved by observing the therapy, which then helped parents to improve parent-child relationship as they could understand and interact with their child better.

Part C: Comparison interview. The findings presented in *Part C* indicate that most of the parents preferred parent-training over direct-therapy. Parents valued the empowering aspects of the training and believed that the training was more beneficial in the long-term than direct-therapy. In terms of the therapeutic impact, parents reported different perspectives. One family viewed that parent-training had more impact on their child, two families were of the view that the direct-therapy made a greater difference, and one family suggested that their child's improvement was the result of the combined effect of both interventions.

Findings in comparison to the previous study of Waddington (2018)

As addressed earlier, the data regarding this analysis is similar to the previous study reported in the doctoral dissertation of Waddington (2018), where she explored parents' experiences of ESDM-based parent-training for parents of five children with ASD. Comparing the contents of the findings reported in each study may be considered of value in providing further insight into our understanding of parents' experiences with ESDM-based parent-training.

In terms of structure, the two studies presented different themes to describe parents' experiences. Waddington (2018) identified four themes: *Effect on child outcomes, model of intervention, parent-training procedures, and relationship with the trainer*. Each theme was

organised into the categories of *strength, weaknesses* and *improvements* to further describe parents' experiences. For instance, in the theme *parent-training procedures*, the positive and challenging aspects of the parent-training techniques, structure, timing and the location of the training were identified as both *strengths* and *weaknesses*, respectively. The suggestions parents made to the training were described in the *improvements* category. In this study, *background factors, facilitating factors, perceived barriers* and *perceived outcomes* were identified. Given the nature of qualitative research that involves researchers' subjective interpretation of data, it is understandable that the way I conceptualised the data is different to the way Waddington (2018) interpreted her data in her doctoral dissertation. The use of a different approach employed in each study also contributes to the differences in how information is labelled (i.e., whether they are labelled as themes or not). Waddington (2018) used a deductive thematic analysis inspired by the theory of social validity, which informed what information would be sought to make up a theme. An inductive content analysis was employed in this study; thus the themes were directly derived from the data itself.

In terms of the findings of both studies, two studies shared some similarities and differences. Firstly, parents in both studies reported a high level of parental satisfaction with the training. This suggests that ESDM-based parent-training is perceived to be acceptable and useful for families of young children with ASD. It is interesting to note that, in this study, parents' negative experiences with other intervention services prior to participating in ESDM-based parent-training are closely associated with high level of parental satisfaction with the training. From this, it is possible to infer that ESDM-based parent-training is not only beneficial for making meaningful changes in young children with ASD but also effective in addressing the needs of parents.

Secondly, a similar finding was reported in both studies regarding home-based training. The current study reported that the home-based setting was one of the important

factors which promoted parental satisfaction with the training. Waddington (2018) briefly reported that home-based parent-training was a preferred choice amongst parents. In both studies, the convenience and familiarity of the home-environment for child were identified as the perceived advantages of a home-based setting. The relevance of conducting training in a home-environment to improve the generalisability of learnt techniques during training was noted in this study as well. Together, these findings support the importance of providing options for parents to choose their preferred location for training. In addition, the use of summary handouts was found to be valued by parents in both studies.

However, some facilitating factors identified in this study were not reported in the previous study, and vice versa. The current study identified the trainer's use of positive feedback and providing an extra person to care for the child during training as other aspects of the training that facilitated parents' positive perceptions. Waddington (2018) identified that parents were appreciative of the immediacy of the feedback, rather than the positive feedback. Waddington (2018) also reported that parents were satisfied with the alignment between their parenting values and the principles of ESDM. Although some parents provided similar information in this study, it was not strong enough to derive a theme or subtheme. In addition, the benefits of the use of an extra person to care of a child during training was not addressed in the previous study. It is possible that some of these elements may not have been utilised in the previous study. For instance, Waddington (2018) reported that parents valued the use of PowerPoint presentation during training which was not mentioned by the parents in this study, suggesting that the delivery method may have changed.

Thirdly, barriers to parent-training identified in the current study are similar to the challenges identified in the previous study. For instance, in both studies, it was identified that parents had difficulty in keeping up with the training content and finding time to practice. Both studies also identified that parents desired additional supports such as having a training

period that extended beyond 12 weeks or additional training sessions towards the end. This suggests that parents may not feel confident enough to implement the ESDM techniques after the completion of training. To this end, it may be useful for future researchers to consider lengthening the training period or providing extra booster sessions and to examine each parent's level of confidence and their fidelity.

The need for a match between individual learning styles and the parent-training techniques was identified in both studies. Waddington (2018) reported that parents valued different training procedures and claimed the importance of alignment between the trainers teaching techniques and parents' preferred method of learning. Similar findings were reported in this study where parents reported different perspectives regarding the use of reflection during training. From this, it is recommended that practitioners' of ESDM-based parent-training may benefit by understanding how parents preferred to learn and subsequently modify their teaching techniques to suit parents' learning style. This may maximise parents' learning potential.

Some barriers to training were found to be differ across the studies. For instance, Waddington (2018) identified parents' difficulty implementing the ESDM techniques with their child, but it was not noted in the current study. Overly technical and American terms in the ESDM parent-training manual were found to be challenging for some parents in the current study. However, more than half (three out of five parents) reported the manual to be helpful in the previous study. It is possible that differing characteristics of participating parents may contributed to this difference. Limited information regarding the characteristics of participating parents in each study limit my ability to offer a clear link between the two factors. Hence, it is recommended that future research may consider obtaining more detailed information about participating parents and examine how it might influence the way each parent experienced ESDM-based parent-training.

Finally, both studies reported similar findings regarding the perceived outcomes of ESDM-based parent-training. In both studies, parents identified various positive outcomes for their child as a result of the training, which included improvement in the areas of expressive and receptive language skills, social interaction and emotional well-being. However, Waddington (2018) only reported child-related outcomes, while this study reported child-related and parent-related outcomes. The findings of the current study suggest that parents felt that an increase in knowledge and skills acquired during training helped them to communicate and interact with their child better, which in turn, led to an improved sense of relationship with their child. The explicit report of parent-related outcomes from the perspectives of parents is a unique aspect of this study which was not explicitly explored by the previous study.

Implication of the findings in *Part A* and *Part B*

Although the structure and the number of themes did differ between *Part A* and *Part B*, the identified themes provided insights into factors that influence parents' positive or negative perception of ESDM-based parent-training and low-intensity ESDM direct-therapy. The themes also captured how parents perceived outcomes of the two interventions. In this section, the main similarities and differences between the two interventions are highlighted and discussed in relation to how the findings can inform the practitioners and developers of ESDM based parent-training and therapy for families of children with ASD. The result of the experimental research of Dr Waddington and her team which the interview data for this study was generated, is discussed in comparison to the findings of this study as well. The manuscript of the experimental research was submitted to a journal in 2020 and it is cited as Waddington et al. (2020) in the discussion below.

Home-based setting. In both ESDM-based parent-training and low-intensity ESDM direct-therapy, parents were highly satisfied with the home-based setting. The parents, who

received the training and therapy in a community centre due to their family circumstances, also expressed that they would have preferred a home-based setting, especially in relation to the frequency of attendance required for the direct-therapy. They reported that while it was manageable to attend the parent-training once a week in a community centre, attending twice a week for therapy was challenging and they recommended having a longer therapy session once a week instead. This finding suggests that a home-based setting is clearly favoured by parents of children with ASD. Due to the small number of participants in this study, further research is needed to generalise the finding of this study. Moreover, the evaluation of the cost-effectiveness of home-based parent-training or an early intervention service is required as it can be costly for therapists to visit families in various locations.

A home-based intervention approach is a highly valued means to improve accessibility for families, especially for those who are socially and financially disadvantaged. Although there is little information about home-based early intervention for families of children with ASD (Grindle, Kovshoff, Hastings, & Remington, 2009), a study regarding early prevention for child maltreatment reported a high family drop-out rate that ranges from 20% to 80%. The intrusive nature of home-visits may account for the drop-out (Guterman, 2000). As a matter of fact, Grindle et al. (2009) found that mothers, who received home-based ABA programme for children with ASD, reported that therapist's presence at home was challenging because of a lack of privacy. Parents in this study, however, did not mention any issues with feelings of being intruded upon by the trainer or the therapist. The quality of the relationship between parents and the service providers may explain these differences. All parents highly regarded the value of their relationship with the trainer and therapist and reported a highly satisfactory relationship with them. The importance of the relationship between service providers and the participating family in home-based early intervention is reported in other research (Brand & Jungmann, 2014; Grindle et al., 2009; Lovaas, 1996).

Therapist related factors. In relation to parent-training, a positive parent-trainer was valued by all parents. Although the level of importance regarding the relationship varied between parents, they all appreciated the personal characteristics and abilities of the trainer and therapist to build a positive working relationship with parents. This finding is consistent with the existing research regarding the importance of the therapeutic alliance in PMI for children with ASD and other disorders (Jackel, Wilson, & Hartmann, 2010; Jackson, Traub, & Turnbull, 2008; Kazdin, Marciano, & Whitley, 2005; McLeod & Weisz, 2005; Myers, 2008).

Interestingly, some parents reported that the relationship between the trainer and their child was important as it provided an assurance for the effectiveness of the ESDM techniques. An opportunity for the trainer to interact with the child during parent-training was also valued as the trainer may thus understand what it was like for the parents to interact with their child. These findings suggest that including more opportunities for trainers to interact with children as well as parents during parent-training may have a positive effect on parents' perceptions of the usefulness of parent-training. Further research is required to clarify this effect.

In relation to the direct-therapy component, parents provided varying descriptions of their child's relationship with the therapist as ranging from poor to highly positive. Moreover, some parents reported a subtle misalliance with the therapist. For instance, some parents reported that the therapist's use of certain techniques did not match their parenting values or their child's tendency. They stated that it was difficult for them to discuss it with the therapist as they felt it may interrupt the flow of the therapy or purpose of the research. It was interesting to note that parents had a regular discussion with the therapist at the end of each session, but they did not express such concerns with the therapist. This finding suggests that

the therapist may need to ask more directly about any challenges the parents may face during the therapy.

Feedback. The importance of therapist feedback was noted in relation to both interventions, but parents valued different styles of feedback in each intervention. In the parent-training, parents highly valued the importance of the therapists' positive feedback. It is consistent with previous research finding regarding the importance of fostering parental self-efficacy through training. Raj and Salagame (2010) used a sensitised coaching model for parents of children with ASD to facilitate parents' self-efficacy. The training was carefully designed to provide opportunities for parents to experience success in implementing learnt techniques in different contexts and settings. As a result, parents in the sensitised parent-coaching model demonstrated greater task-specific self-efficacy than parents in a typical parent-training model. This suggests that parent-training that focuses on positively reinforcing parents can help not only to promote parents' satisfaction with the training but also to improve their self-efficacy. This is also useful information for the practitioners of ESDM-based parent-training to keep in mind.

In relation to direct-therapy, parents found the overly positive feedback was not helpful and instead desired more balanced, specific and constructive feedback. Parents reported that they needed a clear overview of what worked and what did not, so that they could work alongside the therapist to support their child. The contrasting preference regarding the type of feedback may be related to the role of parents in each intervention. In parent-training, parents may have been placed out of their comfort zone and required time and support to build their confidence. In the context of direct-therapy, their role was not only to observe the therapy but also implement the techniques learnt during parent training. For this, it is possible that parents desired more accurate and specific feedback from the therapist.

Child-related outcomes. In relation to both the parent-training and the direct-therapy, most of the parents reported that their child showed gains in the areas of communication, social engagement, and reduced levels of stress and behavioural difficulties. The findings of this study are consistent with previous research regarding the outcomes of ESDM based therapy or parent-training (Dawson et al., 2010; Rogers et al., 2014; Vismara et al., 2018; Vismara & Rogers, 2008; Waddington et al., 2016).

In relation to direct-therapy, parents from two families reported that it was difficult to isolate the therapy as the sole contributor to their child's gains, as the parents themselves and others provided the ESDM intervention to their child outside of direct-therapy hours. This was also addressed in the experimental study where Waddington et al. (2020) identified that the effectiveness of the direct therapy was inconclusive for the same reason.

Parent-related outcomes. All parents endorsed the acquisition of new skills and knowledge as the main benefit of participating in the parent-training. Although it is expected, what is interesting is that this increase of knowledge and skills helped parents to understand and communicate with their child better, which in turn then helped them to improve their relationship with their child. Research regarding the experiences of parents of children with ASD consistently report that mothers of children with ASD are more likely to have difficulty understanding and managing their child's behaviours than mothers of typically developing children (Ludlow, Skelly, & Rohleder, 2011; Tunali & Power, 2002). Such difficulties were identified as the primary source of parenting stress (Phetrasuwan & Miles, 2009). It is possible that providing ESDM-based parent-training expanded parents' knowledge in understanding their child's diagnosis and behavioural symptoms associated with ASD, which then helped parents to understand their child's difficult behaviours in a more realistic way.

Interestingly, only two families identified gains in knowledge and skills from direct therapy. This may be explained by the difficulties that parents expressed in relation to

observing the therapy during the direct-therapy phase. The lack of clear expectations or explanation about what to expect and observe left parents wondering what to observe and learn. The presence of parents during therapy also distracted their child at times, thus parents were more likely to remove themselves from the opportunity to observe the therapy. In the experimental study, Waddington et al. (2020) encouraged the observation as a possible means to maintain parents' fidelity. This indicates that, in order for parents to increase or maintain fidelity through observation, the therapist may need not only to work with children but also to communicate actively with parents. Consideration regarding how the observation will take place is needed as it is likely that children will engage with parents if parents are to be present during therapy.

Implication of the findings in *Part C*

The findings of *Part C* indicate that parents in general preferred receiving ESDM-based parent-training over low-intensity ESDM direct therapy if they were to choose only one of them. A higher level of parental involvement and the long-term benefits of parent-training were offered as the rationale behind their choice. Parents' preference regarding parent-training can be understood in relation to parents' dissatisfaction regarding early intervention services. In many early intervention studies, parents identified their struggles to find an opportunity to be involved in therapy for their child and a need for support to understand the information provided by professionals (Applequist & Bailey, 2000; Lovett & Haring, 2003; Shannon, 2004). ESDM parent-training is shown to be meeting parents' desire to be actively involved in their child's therapy. It is also possible that the training may have improved parents' understanding of ASD and helped them to communicate with professionals better. Through training, parents were taught basic knowledge of ASD and specific ESDM skills that require to improve children's communication, social engagement,

imitation and etc. This may have influenced parents to perceive more benefits from the parent-training than the direct-therapy.

Furthermore, it is possible to assume that perceived child outcomes may have influenced parents' preference for parent-training. Most parents identified the improvements their child made in relation to the parent-training, but only two families positively identified the gains their child made as a result of direct therapy. Given the nature of this study, the data obtained is rather descriptive and focused on parent's experiences rather than the outcomes of the two intervention approaches. Therefore, this study is limited in its capacity to clarify whether parents' preference for parent-training is indeed influenced by the perceived child-related outcomes. A further investigation in this topic is warranted.

It is also important to acknowledge that parental preference is closely related to parents' perceived confidence and abilities to learn and implement ESDM techniques. One mother, who had difficulty engaging in parent-training due to her challenging family circumstances, reported that parent-training was not suitable for her and identified the direct-therapy as her preferred choice. This finding suggests that assessment for suitability of parent-training may be needed to maximise the therapeutic effect of ESDM-based parent-training.

The preference for parent-training did not correspond with the perceived impact of parent-training. Parents from three families reported that the therapist made more meaningful impact on their child's improvement than parents themselves. It was believed that the therapist had more knowledge and better skills, thus the therapist could deliver intervention with higher fidelity than the parents themselves. Parents from one family viewed that their use of the ESDM techniques at home with their child made more impact than the therapist's. It was believed that they could implement the therapy consistently for longer hours than the therapist. This finding suggests that parents' preferences are not necessarily related to the

effectiveness of the intervention. Future research is needed to investigate these findings and improve our understanding regarding what exactly influences parents' preference of ESDM-based parent-training over therapist delivered ESDM therapy.

Lastly, it was interesting to note that, in the experimental study, Waddington et al. (2020) found that the parent who identified more gains in their child from the parents' use of ESDM techniques showed a lower level of fidelity than other parents. Interestingly, parents perceived that there was no difference between their use of ESDM techniques and the therapist's. This suggests that the actual level of fidelity may differ from how parents perceive their own level of fidelity. Further research is required to clarify this.

Strengths and limitations

The main strength of this study is that the analysis of parents' perceptions of ESDM-based parent-training and low-intensity ESDM direct therapy was conducted independently using interview transcriptions provided by an external research team outside of the University of Canterbury. The use of secondary data collected by other researchers provided a unique advantage. Being uninvolved in the process of providing the training, or interviews meant that the analysis was conducted from a distance with a reduced risk for potentially biased interpretation.

However, it is important to acknowledge that the use of secondary data has a distinct challenge, since the analysis is not part of the data creation. As it is believed that the interaction between researchers and participants is a crucial process in generating meaningful interpretation of qualitative data, the use of secondary data gathered by others may result in a loss of authenticity and adequacy in data-interpretation (Irwin, 2013). It is particularly true if an analysis was conducted without an endeavour to understand the meanings and context of a given data set.

To minimise this risk, I conducted a background research to be familiarised with ESDM-based parent-training and direct-therapy by reading the ESDM manuals, relevant literature, including the previous work of Waddington (2018) and the information provided by the external research team (Waddington et al., 2020). Furthermore, meaning units were identified in the entire interview transcripts, including verbal and non-verbal expressions of both interviewees and interviewers. In this process, I endeavoured to be fully immersed into the given data and to understand the meaning and context of what parents expressed in the interviews.

The data that was provided for me was based on semi-structured interviews. The role and intentions of the primary researchers are more likely to be transparent in semi-structured interviews than ethnographic enquires and field work (Irwin, 2013).

Applying an inductive approach to interview data that is designed to elicit specific information regarding ESDM-based parent-training and low-intensity direct-therapy was an interesting but challenging aspect of this study. Although I strived to achieve as inductive as possible an interpretation of parents' perceptions and experiences, the findings of this study are, by nature, tied to the intentions of the primary researchers who designed and conducted the interviews with parents. However, approaching the data with open-mind and analysing parents' spontaneous comments that were not directly related to the interview questions elicited novel aspects of parents' perceptions that were not captured in the previous study.

In addition, this analysis is limited in that parents' perceptions and experiences with ESDM-based parent-training and the therapy are only representative of the parents who were willing to participate in the experimental study of Waddington et al. (2020). Indeed, a high level of motivation and commitment was noted amongst the participants of this study. Therefore, it is possible that the findings of this study is limited in its ability to explain what promotes and maintains the engagement of parents with low-levels of motivation

Finally, the analysis of this study proceeded with minimum involvement of the Dr Waddington's research team. The outcomes of the experimental study were to be kept unknown until the completion of the analysis. It was to prevent myself from analysing data with pre-conceived ideas influenced by the objectives or the results of the experimental research. Reflecting back, however, it is possible that opening a dialogue with the primary researchers in the process of developing codes and themes may have been more beneficial in producing context-rich interpretation of the data. Also, it may have enhanced the dependability of the findings of this study.

Implications for future research

Based on the findings of this study, it is recommended that the next step in this area of research is to explore multiple perspectives beyond those of parents. Understanding parents' perspectives regarding facilitating and barrier factors of parent-training is crucial in supporting parents to continue using and implementing PMI. However, perspectives of parents represent only half the picture for developers to enhance and refine ESDM-based parent-training. The other half comprises practitioners' perspectives. In this respect, future research should consider exploring what advantages and challenges the practitioners may perceive with training parents to deliver the ESDM techniques. Moreover, it is suggested that particular attention should be given to comparing and contrasting perspectives of parents and practitioners.

Also, the use of focus-group discussions to explore parents' perceptions is recommended. Focus groups are effective in fostering free expression and sharing of ideas amongst participants, while minimising the influence of interviewers (Morgan, 1996). Gathering information in a group setting may provide additional information and it may make the shared perceptions and experiences of ESDM-based parent-training to be more visible as parents actively interact with each other through discussion.

Conclusion

The findings of this study demonstrated that, in the perspectives of parents, ESDM-based parent-training is an acceptable and satisfactory form of early intervention service, which is consistent with the previous study. It is also found that parents' unmet needs and dissatisfaction with existing intervention/support services for their child with ASD appeared to be adequately addressed by ESDM-based parent-training. As it is only the second qualitative analysis on parents' perceptions of ESDM-based parent-training in New Zealand, more research with greater number of parents from a wide cultural and ethnic background is needed to generalise the findings.

The findings regarding parents' preference of ESDM-based parent-training to low-intensity direct ESDM therapy indicates that parents perceive greater benefits with parent-training than low-intensity direct therapy. To strengthen these findings, it may be useful for future researchers to conduct a research with two groups of parents receiving either ESDM-based parent-training or low-intensity ESDM therapy and examine parents' perceptions of the two interventions.

CHAPTER 6

GENERAL DISCUSSION

This chapter discusses the findings of this thesis in relation to parents' perceptions of PMI. Specifically, it integrates Part A in Study 2 (parents' perceptions of ESDM-based parent-training) with the qualitative systematic review and synthesis presented in Study 1. Because the analysis of parents' perceptions of low-intensity ESDM direct-therapy was confined to Part B of Study 2, it is discussed within Chapter 5.

Main Findings and Implications

The main purpose of the presented thesis was to gain an in-depth understanding of parents' perceptions of PMI. To full fill this purpose, this thesis conducted two studies. Study 1 was a qualitative systematic review and synthesis, which explored and critically synthesised the existing findings regarding parents' perceptions of PMI across different parent-training models. In this study, I wished to provide the readers of this thesis with a broad understanding of how parents generally perceive PMI. Part A of Study 2 was a qualitative analysis of ESDM-based parent-training. This study explored parents' perceptions of a specific form of PMI. By conducting these two studies, I expected that the findings in Study 1 and Study 2 might complement each other and further our understandings about the values of PMI from the perspectives of parents.

In both studies, similar themes emerged which reflected the factors which facilitate and barrier parents' engagement with parent-training. In terms of facilitating factors, findings in both studies identified that a trainer (a provider of parent-training) plays a key role in facilitating parents' engagement. Both studies indicated that parents value clinical skills and knowledge of a trainer as well as his or her personal attributes and abilities to build a positive parent-trainer relationship. From this, it is recommended that the training provided for professionals (trainers) for PMI needs to focus not only on skill development but also on

professionals' abilities to build a positive therapeutic relationship with parents. Similarly, flexible scheduling and easy accessibility valued by parents in both studies indicate that the providers of parent-training should be more conscious of allowing systematic and structural flexibilities regarding time and location of the training sessions to take place.

It was interesting to note that group-based parent-training was found to be one of the preferred forms of parent-training in Study 1. Although Study 2 did not identify a need or preference for a group-training format, it may be an interesting area for future research in relation to ESDM-based parent-training. From the perspectives of service providers, a group-training format is found to be more cost-effective than an individual and face-to-face format of training (Anan, Warner, McGillivary, Chong, & Hines, 2008). In Study 1, parents also value the opportunities to be connected to other parents of children with ASD through a group-based training. Given the lack of supports and negative experiences related to the stigma of autism found in Study 2, group-based training may be of value for parents of young children with ASD in New Zealand context as well.

In terms of factors acting as barriers, both studies indicated that parents experience difficulty coping with the demands of the training, suggesting that extra support may be necessary for parents to master and implement the evidence-based early intervention techniques with confidence. Interestingly, the findings regarding the lack of fit between individual learning style and training techniques used by a trainer indicated that providing individualised training may promote parents' engagement better.

Furthermore, the findings in Study 1 suggested that parental satisfaction with parent-training was related to how well the training met parents' emotional and informational needs. Although it was unclear whether ESDM-based parent-training provided adequate supports for parents' emotional well-being, the skills and strategies provided in ESDM-based parent-training appeared to be appropriate for meeting parents' informational needs. In Study 2,

parents identified a positive impact of learning new knowledge and techniques to make a meaningful change in their child.

In terms of the perceived outcomes of PMI and ESDM-based parent-training, acquisition of new skills and knowledge were identified as the main benefits of the training. As described in Study 1, the increased knowledge and skills positively related to an improved sense of empowerment, which then translated into an improved sense of parent-child relationship amongst parents in Study 2. From this, it is possible to assume that the underlying mechanism of how parent-trainings makes meaningful changes in parents and their child may be common to a various models of parent-training. Further research is needed to explore this topic.

Conclusion

PMI is one of the promising intervention approaches that can address the limitations and challenges associated with the existing early intensive interventions for children with ASD. Training parents to deliver this evidence-based early intervention can reduce families' financial burdens associated with accessing and maintaining costly early intensive intervention services for a long period of time (Leaf et al., 2017). It may also release the pressure of the providers of early intervention services as parent-training requires a shorter period of time for professionals to engage with each family than a typical early intervention which is directed at each child. For this reason, the topic of PMI has received a great deal of interest from many researchers. Although the rigor of the findings regarding the effectiveness and feasibility of PMI is relatively weak (Oono et al., 2013), many studies have claimed its effect in improving some areas of functioning in children as well as the quality of parents' lives (McConachie & Diggle, 2007; Siller & Morgan, 2018). The findings in Study 1 and Study 2 provided an in-depth description of the positive impacts of PMI in parents through exploring parents' perceptions and experiences of PMI. In particular, Study 2 suggests that

ESDM-based parent-training is a highly acceptable and valued form of intervention for parents of young children with ASD and preferred over direct-therapy.

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APPENDIX A

Appraisal of the Included Studies Using Mixed Method Appraisal Tool (MMAT)

Table A.1

Result of appraisal of the included studies using the MMAT

		Qualitative studies								**Mixed-method studies**						
Type of study	**Methodological quality criteria**	Brezis, et al. (2015)	Chlebowski, et al. (2018)	Donaldson, et al. (2011)	Foster, et al. (2013)	Freuler, et al. (2014)	Hodgson, et al. (2018)	Patterson & Smith (2011)	Wallisch, et al. (2019)	An (2017)	Cutress& Muncer (2014)	Dillenburger, et al. (2004)	Hodgetts, et al. (2013)	Pickard, et al. (2016)	Rivard, et al. (2017)	Stahmer, et al. (2017)
Screening questions	S1. Are there clear research questions?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
	S2. Do the collected data allow to address the research questions? (sic)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Qualitative studies	1.1. Is the qualitative approach appropriate to answer the research question?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y		Y	Y	Y	Y
	1.2. Are the qualitative data collection methods adequate to address the research question?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y		Y	Y	Y	Y
	1.3. Are the findings adequately derived from the data?	Y	Y	Y	N	Y	Y	Y	Y	Y	Y		Y	Y	Y	Y
	1.4. Is the interpretation of results sufficiently substantiated by data?	Y	Y	Y	N	Y	Y	Y	Y	Y	N		Y	Y	Y	Y
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	Y	Y	Y	N	Y	Y	Y	Y	Y	N		Y	Y	Y	Y
Quantitative Descriptive studies	4.1. Is the sampling strategy relevant to address the research question?									Y	Y		Y	Y	Y	Y
	4.2. Is the sample representative of the target population?									N	N		N	N	N	N
	4.3. Are the measurements appropriate?									Y	Y		Y	Y	N	Y
	4.4. Is the risk of nonresponse bias low?									Y	N		N	N	N	N
	4.5. Is the statistical analysis appropriate to answer the research question?									Y	Y		Y	Y	Y	Y
Mixed method studies	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?									Y	N		N	Y	N	Y

	5.2. Are the different components of the study effectively integrated to answer the research question?		Y	N		Y	Y	N	Y
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?		Y	N		Y	Y	N	Y
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?		Y	Y		Y	Y	Y	Y
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?		Y	Y		Y	Y	Y	Y

*MMAT, Mixed Methods Appraisal Tool; N, no; Y, yes; CT, can’t tell

Table A.2

Modified screening question 2 (S2): Do the collected data allow to address the research questions (sic)

	Qualitative								Mixed-method						
Methodological quality criteria	Brezis, et al. (2015)	Chlebowski, et al. (2018)	Donaldson, et al. (2011)	Foster, et al. (2013)	Freuler, et al. (2014)	Hodgson, et al. (2018)	Patterson & Smith (2011)	Wallisch, et al. (2019)	An (2017)	Cutress& Muncer (2014)	Dillenburger, et al. (2004)	Hodgetts, et al. (2013)	Pickard, et al. (2016)	Rivard, et al. (2017)	Stahmer, et al. (2017)
1. If the setting for the data collection was justified	N	N	N	N	N	Y	N	Y	N	N	N	N	N	N	Y
2. If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. If the researcher has justified the methods chosen	Y	Y	N/A	Y	N	Y	Y	N	Y	N	N	N	Y	N	Y
4. If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Y
5. If methods were modified during the study. If so, has the researcher explained how and why	Y	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Y	N/A	N/A	N/A	N/A	N/A	N/A
6. If the form of data is clear (e.g. tape recordings, video material, notes etc.)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	N
7. If the researcher has discussed saturation of data	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	N	N

Table A.3

Modified question 1.3 of qualitative studies: Are the findings adequately derived from the data?

	Qualitative								Mixed-method					
Methodological quality criteria	Brezis, et al. (2015)	Chlebowski, et al. (2018)	Donaldson, et al. (2011)	Foster, et al. (2013)	Freuler, et al. (2014)	Hodgson, et al. (2018)	Patterson & Smith (2011)	Wallisch, et al. (2019)	An (2017)	Cutress& Muncer (2014)	Hodgetts, et al. (2013)	Pickard, et al. (2016)	Rivard, et al. (2017)	Stahmer, et al. (2017)
1. Is there an in-depth description of the analysis process	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Is thematic analysis used. If so, is it clear how the categories/themes were derived from the data	Y	N/A	N/A	N/A	Y	N/A	N/A	Y	Y	Y	Y	N/A	N/A	N/A
3 Does the researcher explain how the data presented were selected from the original sample to demonstrate the analysis process	Y	Y	Y	N	N	Y	Y	N	Y	N	N	N	Y	N
4. Were sufficient data presented to support the findings	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
5. Were methods modified during the study. If so, has the researcher explained how and why	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
6. To what extent were contradictory data taken into account	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Y	Y	Y	CT	N/A
7. Has the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation	N	Y	Y	Y®	Y	Y	N	Y®	Y®	Y	Y	Y	Y	Y

APPENDIX B

Summary of the Included Studies

Table B.1

The research questions and key findings of the included studies.

Study/Setting	Research questions & Key hemes
An (2017), South Korea	**RQ:** Does this parent training approach to treatment improve the occupational performance of the child, the parent, or both the child and parent? What are the parents' perceptions and expectations of parent training? **1) New learning** a) *learning more about their own child, general child development and how to identify and support their child's occupational performance needs* "how little they knew about their child, about their needs, and how to assist them" b) *Learning specific strategies to use interacting with their child* "I cannot believe that I have learned how to feed MC food other than rice, beef and water" c) *reported feeling "relieved and satisfied"* when they had learned specific skills in facilitating their child's occupational performance *d)* *gaining insight about themselves, their own perceptions about their child, anther interaction with their child based on their low expectations* **2) Shift in parents' attitudes and expectations** a) Attitudes shifted from "my poor baby with a disability who can't do anything" to "my child who can be assisted to participate in their daily activities" =>leading higher expectation of their child which in turn had positive impact on child OP b) Improved interaction with their child as a result c) Feeling less stressed interacting with their child. They felt empowered to find ways to facilitate their child OP **3) Living with Autism in Korea** *a)* *The stigmatization, lack of support, feeling of isolation, and feeling bounded all day to their extremely dependent child with autism* b) "Autism is still not accepted in our culture; you know we don't use the word 'autism'. People prefer to use the term "borderline children' instead of autism" c) Avoiding family and social functions since they received the diagnosis *feeling isolated and feeling unable to be out in the public with their child* d) *Feeling overwhelmed and stressed.* Their entire day evolve around the needs of the child with autism, taking them to various therapies or taking care of their daily activities with no support

4) Desire for future direction and guidance

a) Expressed continued needs for support and have the therapist to be authority to set goals and provide specific home programme
b) Reported feeling incompetent and unqualified in setting goals for their own child and preferred to defer to the expert
c) Feeling comfortable in being told what to do by the "expert professionals"

Brezis et, al. (2015), India

RQ: The study aimed at capturing the transitional moment of autism in India while providing evaluation of PCIT service that train parents of children with autism

1) Differences in parents' narratives before and after the programme

a) Less likely to mention other people and children, the child's siblings or compare their child to normal standard
-> indication of increased level of acceptance of the child's condition and focus on positive behavioural management
b) More parents spoke of growth and changes
Changes in their child
"she used to not give attention to me; now she comes to me, sits on my lap also, hugs me tightly as well"
c) Changes in their own perception and understanding of autism
"my perception about autism has changed a lot … paarth's behaviour tantrums that were 3 months ago, which used to occur 2-3 times a day.., now I should say that it happens oce or twice in a week…, this means I have ben able to understand his behaviour quite well. [before the PCTP} I didn't pay much attention to why, I have been able to tackle this quite well, and the bonding between me and him has also strengthened, and I am feeling quite positive after this. And I feel that paarth has also become more attached to me"
d) Mentioned more about future and their wishes
i) "I want him to be independent", "I want to send him to school"
=>positive outlook to future

2) Differences in mothers and father's topic mentioned

a) Mothers
i) reflection of their relationship
ii) observation of relationship being difficult to neutral, positive
iii) many mothers describe a positive relationship despite their difficulties
iv) Some mothers reflected a subtle shift in their perspective
"earlier I was so worried, because my son cannot even recognize me. But now [I understand that] he is slow, yet he will be able to learn later"
"I didn't understand how I can handle [my child]. Then I came here, then I know all these [ways] how I can handles things. If I put things in a structure or schedule, life will be a lot easier"
b) Fathers were more likely to mention their spouse

Chlebowski et, al. (2018), USA	**RQ:** Aim of the study was to examine therapist and Latinix parent perceptions of therapist-parent interactions and the intervention process when community therapists are trained to deliver AIM HI (An individualised Mental Health Intervention for ASD)

1) Limited ASD knowledge and need for psychoeducation

a) "there's a lot of parents do not have information when they [their children] first get diagnosed with the autism. They do not know how the child is going to develop or what's going to go on. Like when my first child, when he was diagnosed, **it was devastating**. Because you didn't know where he was ever going to grow to be able to function by himself"

b) Parents identified the *challenges of participating in treatment without initial ASD knowledge* and the need for therapists to provide information early in treatment
"what happens is that, it's because of lack of information from the parents not knowing, and when the therapist starts saying things, the people get confused because they do not know"

c) Parents identified higher needs for general psychoeducation about ASD than the treatment or resources available for their child

2) Expectations of parental involvement

Parents saw themselves *have an active role in their child's treatment*
Expected to be highly involved in their child's treatment

a) ***Reason for participation*** to the programme is *to learn new skills for themselves*
   i) "to learn, listen, understand, and practice in the therapy activities"
   ii) "parents as much as possible and try to learn, take the opportunity to learn how to handle situations and how to deal with children and how to help them, because sometimes you don't know how to help them"
   iii) Reason for participation = *to increase their understanding of their child and the ASD diagnosis*
   participation helped her "at certain times, to feel like him [son], to be able to understand him more"
   "be in the shoes for my son to be able to understand it [autism] more"

b) Prioritised the participation
   i) "I think *that parents are important, but I think that most importantly are both the therapists and the parents.* because the therapists are the ones who impart the therapies and help them [the children] and *us as parents also help the therapists by performing the work at home…* because like I'm telling you, it's not so much yes, I know that they're the ones [the children] who need the help, the attention and everything, but *we are the ones who help them, the ones who are living everything for them*

3) Influences on parent-therapist interaction

a) The factors influencing parent-therapist relationship
= personal connection with the therapist
= development of trust and mutual respect (essential)
"we had a relationship of trust, it is as if I was talking with a friend, she made me feel as a friend, as someone who I could trust, as someone who listens to me and is not criticizing or watching to see what I'm doing wrong or what I do wrong"
= warm and friendly demeanour
= expressed personal interests in their lives and the lives of their children

b) Suggestions

	i) "I think that human quality , knowing that [the therapist] understands, give us the confidence to feel comfortable in asking [questions], knowing that he [therapist] as a professional also is sympathetic to what you are going through, that would help a lot" ii) "families need confianza not to feel ashamed of what happens in the session at times, of what the children do" iii) "I think that the trust was a bit lacking. Maybe we felt the relationship etween the therapist and us [parents] was a little cold, and sometimes that would inhibit us from being able to express to her what we may have felt or wanted in that moment"
Cutress & Muncer (2014), UK	**RQ:** Aim of the study was to report parent's view of the EBPP (Early Bird Plus Programme) as decisions about attending the programme are made by the family, as well as evaluating parents' perception of their learning during the EBPP and their general experience of the programme.
	1) Learning about autism a) *Knowledge about the condition* =understanding the symptoms and lifelong nature of ASD b) *Specific strategies the parents had learned* =use of visual supports, analysing behaviours and managing challenging behaviours c) *Coping with children's condition (coping strategies)* =being patient, seeking appropriate support and sharing experiences with other parents **2) Learning about communication** a) Strategies to improve communication =social stories, giving choices b) *How communication differs from children with ASCs* =difficulties with non-verbal communication in children with ASCs c) *How parents need to adapt* =reducing or simplifying their language, allowing more time, being patient d) *General learning about communication* =communication is not just language but more **3) Learning about behaviour** *a) Why behaviour occurs* *b) Specific strategies parents had learned to manage their child's behaviour* c) *How parents' view of behaviour had changed* =acknowledged how their own behaviour impacts on their children and that there are reasons for their child's behaviour d) Messages for other parents/ professionals e) Child-focused outcomes *=programme helped parents understand their child's needs and facilitate child development* f) Parent- and family-focused outcomes *= reduced parental stress and improvements in family life, feeling empowered and more confident*

	g) Benefits of meeting other parents and professionals *=helpful to meet other parents in the same situation and share experiences* *=benefits of using consistent techniques at home and school* "gave us more understanding and made us work better as a team. Also made our relations with the school professional a lot stronger"
Donaldson et, al. (2011), USA	**RQ:** Aim of the study was to describe in rich detail how fathers of children with autism perceived their parental roles and discover whether father perceived the FDIT (Elder's Father-Directed In-Home Training) intervention and if they viewed it as effective in enhancing their father roles and relationships with their children.
	1) **Sharing time** a) asked question about what made them feel like a father b) shared time made them feel most like a father i) "he really likes when I, you know, pick him up and play monster or throw him up in the air or throw him across the pool. You know, I was like; this is what dads do" "just coming home from work and having boys come and say "daddy" and sit on the couch" **2) Having a close relationship** a) Fathers stated they cherished the time they spent with their children and that the relationship was improving on a daily basis. i) "our relationship is very strong, I know how to reach him and how to interact with him and how to have fun with him" *b) Importance of communication* i) "I am a lot happier now that he found sign language and PEC. I feel a lot more like a real relationship now that we can communicate" **3) Accepting the diagnosis** a) Initial lack of knowledge or information about ASD b) Initial reaction to the diagnosis = denial, disappointment about expectations of the hope for the future c) Sense of relief about knowing **4) Concerns of, and hope for, the future** a) Concerns about their child's development such as whether their children will be able to live independently and be accepted by society given the severity of the disorder b) Sense of hope i) "I think we've come a long way.. the older he gets, I think he's getting better. It's just baby steps, but I see forward progress I can see the light at the end of the tunnel" c) "hopefully he'll be talking by then" d) "I am cautiously optimistic" **5) Benefits of the programme** *a) Direct benefits = learning how to help their child learn and seeing an increase in communication*

	i) "I've learned some teaching techniques that have helped in dealing with him… I've learned is to let him lead and to help him learn through his best way of learning, now necessarily the way I think he should learn" b) Expressed feelings about using the techniques they learned *c)* *Indirect benefits= quality time spent with the child* i) "the best thing about the programme is that it made me make time to spend and focus on my son…. I think the programme has drawn he and I closer together because he sees that I am more than just a disciplinary figure.. It's kind of brought me more into the nucleus [of the family] than I probably was before and it's great"
Foster et, al. (2013), USA	**RQ:** Aim of the study was to systematically explore how mothers used their insight from the coaching process in their daily lives in order to understand how mothers experienced coaching and how coaching leads to change
	1) Mechanism of change: Relationship *a)* *Positive parent-therapist relationship & reflective questions =>promoted opportunities for parents to analyse challenging behaviours* b) Parent-therapist relationship is *fundamental to communicate openly, to share knowledge, reflect and analyse activities* "I think the one-one-one helped a little bit more than just, you know, sometimes the therapists would have an IEP goals but then you don't really sit down and talk about them for another, you know three or four months or its kind of in passing" c) *Appreciated talking with a therapist who was objective and outside of their social/family circle* "I was glad to have someone who understand s to go to for advice, without any kind of …[sigh]… none of the drama when you talk to other parents" **2) MC: Analysis** "talking about it on a weekly basis or whatever that it made me more aware of what was going on" "analysing with you and brainstorming what the most important elements that we need to focus on was helpful" "I think most of the parents can identify better [with] somebody that sees them once a week for an hour…, what the true issues are" **3) MC: Reflection** "it just made me more aware of the differences and what works and why. And I understood more about why we were trying certain things" "this time I came up with the ideas and I understood the basis for those ideas. And how we came to those ideas to ty. Because I did it" *a)* *Importance of having the opportunity to reflect on what they tried* "questions and dialogue, I have a process of stepping bac, analysing and going, thinking about my own experience, ideas and [I am] more proactive than doing it the same way over and over again and getting frustrated" **4) Coaching outcome: Mindfulness** a) The effect of coaching *is beyond the learning new skills* "I am seeing growth. You know so I am no longer looking at whatever he's doing as a permanent fixture. I am looking at it as, okay, this is something that I'm gonna try to help him identify. And maybe we'll get it right away and maybe it'll take time but I'm not gonna assume that how he is now in this moment, is how he's gonna interact with the world forever"

b) Mothers *became more mindful of the contextual factors that influenced her child's performance*

5) CO: Self-efficacy

a) Outcome of the coaching was *"help empower mothers to figure out ways they can improve the quality of their life and their kids*"

b) *By being mindful & solving problems proactively, mothers reported an increased sense of self-efficacy*

"the purpose of the coaching was for empowering parents and giving them the confidence so then they don't feel helpless and hopeless and throw their hands up"

c) *Felt empowered when they could generate their own interventions*

d) approach problems proactively than out of depression is important

Freuler, et al. (2014)

RQ: Aim to explore the experiences of caregivers following their participation in a randomised controlled trial of Adapted Responsive Teaching

1) Working against all odds

a) *On-going struggles to be heard about their early concerns surrounding their child's development and a search for validation for these concerns*

i) -early barriers faced in trying to get validation for her early diagnosis
"wait-and-see" attitude from the father or extended family members
paediatrician either had no concern or appeared dismissive of parent's concerns about the child's development

2) Getting the ball rolling

a) *Enrolling in the study appeared to have an effect of initiating the beginning of either EI or, at minimum, education about available services*

b) Some reported having early concerns described feeling that they did not know where to start

c) *The idea of "setting the stage" for future intervention and therapy experiences*
-facilitated parents level of comforts with therapists coming into the home & eased any ambiguity surrounding the process and purpose of various interventions

3) Value of the personal relationships with professionals as being the key to their buy-in to intervention as well as their evaluation of their overall experience

a) -positive experience with interventionist were related to *validation of their concerns and facilitate feelings of support, feeling a connection with the interventionist, observing a positive relationship between their child and the interventionist*

b) Mother felt "overwhelmed a lot of the time" and supports from the interventionist "was like a breath of fresh air"

c) Having a consistent point of contact was appreciated

4) Getting dad on board

a) Mothers stated
-fathers either did not share early concerns or had a wait-and see attitude.
-stigma that impacted a father's decision not to share diagnostic information with family members

b) Mothers expressed early hesitation to participate in EI

c) Mothers expressed the importance of therapist-child relationship in influencing fathers' buy-in of EI
d) It took both parents being on board to take the part in the studies

5) Positive experiences and burdens
a) *Positive* = developing relationship with EI professionals, feelings of parenting support, increased knowledge of and access to resources
b) *Negative* = burden of traveling to evaluations, anxiety surrounding evaluation outcomes, making time for intervention
c) *Suggestion* = conducting evaluations in the families' homes & connecting parents with each other "talk to other families going through it"
d) Satisfied with offering alternate time to suit family needs

6) Unique theme within the ART treatment group
a) Feeling of win-win being randomised to receive treatment
-feeling relieved that the child receives help
b) Overwhelmingly positive experience of intervention and not harm in getting hep
c) *Help close a gap as well as giving her son an edge as he prepares for school*

Hodgetts et, al. (2013), Canada

RQ: Aim of the study was to investigate the experience and perceived outcomes of Stepping Stones Triple P (SSTP) for parents of children with autism

1) The effect of SSTP on parental self-efficacy
a) **Attribution of cause**
prior to SSTP all parents attributed a least some disruptive behaviours to their child's diagnosis of autism; thus, they did not think that behaviour management strategies would be effective or appropriate.
Feeling guilty about disciplining their child with autism because they felt "sorry for my [child with autism]"
After the completion of the programme; all parents recognised that the challenging behaviour served a function, and was not a symptom of autism. It was empowering for all families.
"It's sort of reassuring. It's like 'Yes, just because they have a disability doesn't mean that they can get away with murder of that you can't have expectations for a certain way to behave'"
b) Who's the boss
Participation in SSTP helped them *to feel "empowered" to expect and demand more positive behaviours from their child with autism,* resulting in the parents *feeling more in charge of their daily routines and activities.*
"Participation in SSTP helped her realised the cycle of negotiation her kids had her in"
"Now he's not the one in charge.. we have him everything before, because we're kind of guilty he's like that … now we're the one in charge! When we say no now, it is really no, we don't give in.

2) The effect of SSTP on parental psychological well-being
a) One thing that parents identified as positively impacting their own well-being was the *focus on rewarding positive behaviours, rather than always focusing on managing negative behaviour*

	3) **Rewarding is rewarding** a) Positive approaches to behaviour management taught in SSTP caused them to *reframe their approach to behaviour management in the context of daily life, resulting in a positive outcomes for their child, themselves and their family.* => achieved by improving interactions and bonding, by allowing them to see their child for who they are, and not as "autism" b) How refreshing it was to reframe how they viewed their children and to focus on reinforcing positive behaviours rather than the seemingly constant "uphill battle" of managing negative behaviours. 'I think the golden nugget I got from Triple P was just when they come to you to show you something or to share something with you. That is just the most important thing in the world and the best time to listen and do some incidental teaching. There's always so much to do like this darn floors … but this is important and they're ready. And thinking of creative rewards is better than always coming up with creative punishments. More positive all around"
Hodgson et, al. (2018), UK	**RQ:** Aim of the study was to explore (1) experiences of participating in a RCT; (2) opinions about the Managing Repetitive Behaviours (MRB) intervention; and (3) impact of the MRB intervention of the participants, their children and the family
	1) Limited knowledge of RRB "Did not know what repetitive behaviours were" before being recruited to, and attending, the MRB intervention. "that was my question actually when I first started, I didn't know, I knew the things that were challenging me but I didn't know they were repetitive behaviours" a) Some went on to suggest that the *MRB intervention could be delivered a soon as possible after a child receives an ASD diagnosis.* *b) They were desperate for advise and support about how to manage their child's behaviour* "But I just went in, just desperate for anything, help from anybody I was willing to take. I just couldn't wait to … I was in just a little vicious circle of not knowing about all the things. So it was lifeline… it really was. c) Would like the course delivered a s an EI, however, some might not be ready to participate immediately after diagnosis when they are still coming to terms with the diagnosis **2) Commitment needed to attend and gain from the intervention** a) -comments about effort they had made to attend and 'get the most out' of the MRB intervention *b) Shared sense of 'being grateful' for the opportunity.* c) "feeling fortunate" - for that they had desire to "put in a lot of effort" so they could maximise their experience and learning -"if you want to get something out of it you've got to be prepared to put something in to it" -"fortunate enough" to receive the MRB intervention had a duty to "do it justice' and make the most of the experience so that others could benefit from this in the future d) *acknowledgement of the flexibility of stuffs* for offering alternative appointment time and venue to suit the needs of family **3) Benefits of a small-size group-based intervention** a) *benefits of "shared experiences" with other parents who were "going through the same things*" "you talk to who isn't in same position as yourself don't understand… and they just see you as pretty much … not an outsider but when you are trying to talk about your children with these people the things are so different between the children"

b) *opportunities for learning from others*
"you get more from the group that what you would get on-on-one, if you were to sit and talk about something just one-on-one to somebody you probably won't expand on all the things whereas you get ideas from all the people jumping in as we do"

4) Homework

a) For some, completing the weekly homework tasks was *feasible and acceptable*, while some *felt it was "a chore" to compete at times*
b) *Recording difficulties* (technology difficulties, child behavioural variation, needing someone else to do the job, difficulty just focusing on negative or upsetting aspects of their children's behaviour)
c) Some endeavour to overcome such difficulties and complete the homework
=*resulting in the enhanced understanding and learning about RRB, increased motivation for parents, opportunity to reflect on their behaviours*

5) Changes in the participants

a) Increased awareness, more knowledge about RRB, feeling more equipped to deal with their child's RRB.
"see the world slightly differently" and "it's certainly made life at home a little bit more relaxed"
b) Helped developing a more realistic view about her sons' RRB & understand that RRB is a part of a lifelong condition and that his RRB will not just stop
"while we've seen marked improvements it wasn't going to go away overnight so I think that, for me, that was the biggest mind-set of all, and how to deal with that… he's always going to have these challenges*, it more how you adapt around him, how you deal with that, rather than making it go away"*
c) Spending more time analysing the situation and thinking 'logically' about what is happening
d) Feeling more optimistic and confident about how to manage RRB
"feel more confident to tackle the issues…we know that we're working through issues in the right way"
e) Gaining new skills and being more aware of my actions

6) Changes in child

a) -*mixed responses*
a reduction in their child's RRB, became more manageable
<->Unable to notice any changes, but had a *sense of optimism or referred on their improved personal self-*efficacy in managing RRB
i) "more understanding and calm with my child"
ii) "I am hopeful with time and strategy that will help"

7) Changes in family life and generalisation of learning

a) *Desire to talk disseminate strategies to other people involved their child's care, such as other family members and teachers*
"the help and advice gained that has been passed to family is helping us all to understand the RRB now and in the future"
b) Improvement in children were due to family becoming more adept at managing RRB

	c) *Able to transfer the strategies to use with other behaviours or situations* "gave you the insight to look at what you were already doing and work out how you could help that overcome something else"
Patterson & Smith (2011), Canada	**RQ:** (1) how do parents describe the challenges and benefits of participating in the More Than Words (MTW) parent-training programme; and (2) how do parents describe the experience of working with the concepts and strategies presented in MTW
	1) Good starting point for learning how to support their children a) "good first step", but needed **2)** ***Clear expectations of child change and parent responsibilities*** -a desire to understand how the MTW impacts a child's development over time -post training expectation ***3) To focus primarily on their child's current stage of communication*** -mix of children at various stages of communication development led to frustration "it kinda felt personal that your child wasn't there at that time" **4) Unmet emotional and informational needs** a) "feeling clueless to start" "it was all so new this autism thing" "emotional baggage" that comes with a child's diagnosis created unique need for ASD information and emotional supports "if parents are emotionally looked after… maybe they'll be better off with their children. Maybe have better response to the communication or things like that" b) =>these needs created questions and frustration that negatively influenced their readiness to absorb and information provided in MTW "more we know, the more we can prepare ourselves…" "wish there was more information" **5) Individualised one-to-one modelling and in vivo feedback mitigates the overwhelming content and learning demands of the MTW programme.** "felt rushed" & "overwhelmed" a) A desire for less content per session leaving more time for open discussion and the opportunity to ask questions "maybe we need a longer period of time cover less aspects in one night so you have more time to discuss it" b) Requested further individualised support i) Critical feedback ii) clinician modelling iii) hands on guided practice

iv) openly view and discuss challenges
(allowing parents to view their videos with the group to discuss troubleshooting..)

6) Parent perceived that their learning and behaviour change was reliant on child factors

a) Initially family described the child as a "little stranger" surrounded by "walls" => their child emerged into a "little character"
"Every day he amazes us. He's talking so much more everyday it's just unbelievable"
<->Caregivers in limited child change, reported multiple child-centred barriers to their implementation of the MTW strategies
child's odd or repetitive behaviours, solitary play and lack of engagement with activities and people
describe their child as "resistant" and wanting to do their "own thing"

b) So little change in their child during their time in the programme that it impacted their "buy in" to EI in general.
"I am still kinda on the fence (regarding EI) because I don't see a whole lot of change

7) The MTW programme provided a venue for parent-to-parent support, which facilitated understanding of ASD and motivation to implement new skills.

"shared experiences" & "someone to talk to"
"even though it was about communication and language [she] thought that parent support was the real reason" for the programme.

"it helped me to interact with the other families. It taught me that I wasn't alone, there are many people going through the same struggles. At the beginning, I thought I was basically by myself you know, dealing with this but actually it's nice to have a group setting and to have other people views and opinions…"

8) The unique learning needs of parents working outside the home and the unique needs of fathers must be considered and addressed by clinicians

"lost out on the coaching". Felt that dads in the group "discussed that a lot, dads had a lot of issues dealing with stuff and were feeling left out" leading to feelings of frustration.

a) Working parents have unique limitations regarding the amount of time they can apply the strategies and practice with their child and that their partners were then responsible for trying to relay information and train them. "double duty" for his wife.
"I only have 2-hours window in the evening with [my son] where [my wife] gets a lot of support during the day, a lot of info, a lot of help. For fathers or mothers that do work during the day who miss out on all that stuff, it would be nice to have a support group… just to get that additional help"

Pickard et, al. (2016), USA

RQ: (1) What are parents genera perception of ImPACT Online?; (2) how does ImPACT Online compare to other services that parents are accessing for their children?; (3) do parents' experience in, and perceptions of ImPACT Online differ based on whether they received a Therapy Assisted or self-directed version of the programme?

1. **Perceptions of the acceptability of ImPACT online**
   a. *Reported positive perceptions about* the acceptability of the programme
      i. "it was pretty straightforward… I think it was set up to meet every different learning style"

ii. "all of the technique were helpful, it was just the timing for my child … it's great to have all of that… in my tool bag, if you will"

b. frequency of the endorsement of the acceptability of the programme was high in TA group than SD group

2. The ease of learning ImPACT online

a. Parents reported that contents were *easy to learn at the beginning, but it became more complex*
=> r*eported the need for support of a coach*
"I think we would have been okay up to a point and then at the end it would have been really, really tough putting it together, because that is when I really relied on the coach"

b. *Group differences* emerged regarding the intervention contents

c. SD group reported that *a background in child development and ASD intervention would be helpful <-> parents in TA group did not*

d. TA group reported
"the coach is watching me as I'm doing it, and it was nice like having second eyes, you know like okay he is doing this so try this, and I would try it. So for me it was that real time to do something different"

3. Relative advantage of having remote access to ImPACT online

4. Agreed *how the programme fits with other services that they were accessing for their child*
5. Intervention technique taught in ImPACT online was similar to other intervention services that they were accessing for their child to increase their child's social communication skills
6. Emphasized the *relative advantage of having flexible access to ImPACT* online *as compared to other services that were delivered in person.* (particular to SD group)
   a. "because it's just really hard with a lot of these other therapies and stuff. It's just so hard to get an appointment that's in the evenings or you know on the weekends. You know it just doesn't happen so it's hard to fit everything in, so at least you can you know learn how to do all this kind of stuff at home or wherever"
   b. "very convenient"

7. Parents and child outcomes

a. *Empowered after learning the intervention techniques that they were better able to interact and play with their child with ASD* and continued to use the techniques after programme completion
"having something like this, I feel like I have power to really help my kid now"
"truthfully it helped me to interact more with him because most the time I let him play by himself"

b. *TA group more likely to report child-focused gains in social communication*
"she was always really snuggly with me, but I definitely feel like we communicate better"

c. *More likely to emphases the generalisation of their use of the intervention strategies across a number of daily routines*
"now were go to do playtime and it's like a half an hour passed and I'm like okay I'm done, I need a break"

8. Perceptions of barriers associated with ImPACT Online

a. TA group = difficulty having a stable connection with their therapist over Skype.

b. SD group = time requirements as a barrier to programme participation and the need to have ImPACT online accessible on tablets and smart phones

9. Parents suggestions for programme dissemination

a. *Programme should be made available to families right at the time of an ASD diagnosis* or even earlier such as when "red flags" are raised for a child

b. Parents felt, although the time of the diagnosis was stressful, many *indicated that access to a programme like this would have helped empower them a provide them with direction during this difficult time*
"At the time you're overwhelmed … I was reaching out to anybody who listened to me, I just needed someone to reassure me basically, and I think that was the most important thing at the time"
"everybody tells you that you have to start intervention and early intervention is key, but nobody gives you anything other than well need to do early intervention, well where the hell do you find that"

Rivard et, al. (2017), Canada

RQ: Aim of the study was to assess the social validity of a training and coaching programme (PCTP) offered to parents wihile their child has been placed on a waiting list for public EBI service.

1. Parent's satisfaction with the programme

a. Satisfied with the programme staff, or the format and structure of the programme
   i. *Appreciation for parental coaching portion* ("tips and advice", "how to act and intervene"), the type of intervention used with their child, the initial training portion, and overall results)
   ii. *Characteristics of staff involved in the PTCT*. ("the staff was professional, their understanding, very satisfied with the therapist) and their flexibility and the openness to parents' contributions ("ask for our opinion" "we are an integral part of the programme"

b. Elements of the PTCT could be improved
   i. programme's *format and structure:* wished for more intensive (hour per week) and frequent (more than once per week) for the programme's duration to be increased
   ii. *Need for improved accessibility*: easier access to, or communication with service providers, access to service provided in language other than French, and shorter waiting period. Additional staff and more staff continuity.
   iii. *Streamlined administration procedures* ("less paperwork to fill out") and *improved coordination* across the various professional services received by their family
   iv. *More flexible coaching schedule*, morning, evening, or weekend sessions
   v. Suggestion for change; with parents *("more training") and with child ("more direct intervention on children")*
      "*difficulty reconciling the behavioural approach with our values")* organisation of public ASD services ("hospital ought to be more knowledgeable about services provided by rehabilitation centrist")
   vi. Requesting more focused interventions

2. Perceived effects

a. Positive effects

	i. the psychological well-being of family members (reduction in stress levels or perceived workload, increased optimism about their child, feeling supported), ii. their parenting skills having structure and goals to work on with the child, having access to data and expertise, having tools and being able to use these appropriately iii. their family's quality of life "our child is more integrated into our family", "this makes our life easier", "there is more harmony in our home" *b.* *negative impact* i. programme demanded too much energy ii. frustration with the insufficient number of hours of intervention iii. feeling more stressed as a result of becoming more aware of the child's difficulties *c.* *impact of the PTCT on their child* i. positive effects: child's daily life and routine (child cleanliness, language improvement, emotional management and social interactions), improvement in cognitive functioning ("better understanding of instructions" autonomy, play, and overall behaviour) ii. undesirable effect: more negative reaction when a request is denied, and problem behaviours have become more difficult to manage.
Stahmer, et, al. (2017), USA	**RQ:** Aim of the study was to examine parent perspectives and the initial impact on parent behaviours of Project ImPACT for toddlers at risk for ASD when delivered by community providers in routine care service settings (1) observe changes in parent use of strategies to facilitate their child's social communication skills for following community-implemented Project ImPACT **(2)** parent perceptions of effectiveness and feasibility of Project ImPACT
	1. ***Parent coaching process*** *a.* *Acceptability of intervention and parent coaching format* *i.* parents reported "believing" in the parent coaching approach and = feeling that their involvement in their child's intervention was important for child progress and => their own feelings of empowerment ii. "it was incredibly useful…because we wanted to be involved …so part of me was that most valuable, because even though he's not meeting with therapist anymore, I know what he should be doing and I know what I can do to help" *b.* *Active parent coaching as critical to intervention* i. =>working with the therapist was one of the most useful aspects of the programme ii. =>seeing the therapist model, the strategies and practice with feedback were identified as especially helpful "the time that we spent together working in the therapy setting was great, because I could watch [the therapist] do the strategies and then she gave me time and real-time feedback on how to do things and then she'd always ask me how it was going" *c.* *Therapist was knowledgeable* i. Parents reported confidence in the therapist' level of knowledge and ability to implement the intervention strategies

"it felt to me like she knew exactly what she was doing and I felt to me like she knew exactly what she was doing and I felt really comfortable that she was going to guide us in the right direction and she did a really good job"

ii. *Strong sense of support from the therapist*

2. Impression of the intervention

a. Intervention considered feasible and useful
b. Parents consistently highlighted the importance of their ability to integrate the approach into their daily live
"I definitely like the fact that you're training the parents to use this in the day-to-day … if it's the two minute increments you can be successful just doing that throughout the entire day"
c. Most useful component of the intervention = "I think that the most useful thing about the training was learning really how to follow your child's lead … to get down on their level and to maintain face to face contact"
d. Felt successful at using this piece of the intervention
"I think I am much better able to follow her lead and to keep her engaged in a fun way in everyday activities"
e. Challenges with the intervention
i. =getting comfortable using the techniques and parent concerns that not all strategies were appropriate for their child's abilities.
ii. =Activities used in the clinical setting were not translating to daily routines at home or public family outings.

3. Treatment planning process

a. Goal developmental process "was very helpful. We were able to talk about goal setting and see where he was at in terms of level of play and language and then we were able to review it at the end and see the progress he made"

4. Homework

a. Challenges finding time to practice the strategies and completing the homework and readings
b. "I didn't see a lot of value in the homework to be completely honest with you. I felt it was busy work, and if you see my book , you'll see it's hardly filled out"

5. Logistics of the intervention format

a. Increased flexibility in scheduling the therapy sessions, lengthening the session duration and improving the orientation to the intervention by including some background theory and before/after videos
b. Opportunities to meet other participating families as they go through the intervention

6. Improved child social communication

a. *perceived effect on both verbal and non-verbal communication and play skills*
"his communication skills have improved dramatically; he's using a ton of word approximations"
b. *Changes in receptive communication skills*
"a lot more eye contact, definitely responding to words, responding to his name, some directions he can respond to"
i. *Increased connections with their children*
"we ow a lot to the programme just in being able to know how to play with our son and engage him and interact with

him and through that, a definite bond has formed that I did not feel that I had with my son before we started the programme"

c. Seeing their child's progress led to their ongoing use of the strategies after they had competed the programme

7. Reduced parent stress

a. Parents *felt reduced stress after the intervention*. Parents who reported decreased stress a*ttributed to their increased comfort level in interacting with their child in ways that may facilitate development.*
"in the beginning when you get that diagnosis and you don't know a lot about it and you don't know what you can do and it's really scary. And after you go through the training you just feel like you can handle this. And there are things you can do to contribute. So I think that helps with the stress"

b. A reduction in behavioural problems as child skills increased also seemed to contribute to reductions in perceived stress for families.
"I think it's [stress] decreased actually. Because I feel more comfortable with my expectations for what he should be doing and wat he is doing. I just feel more comfortable about that'

Wallisch et, al. (2019), USA

RQ: Aim of the study was to explore the lived experiences of parents following participation in a 12-week telehealth intervention using occupational based coaching

1) Compatibility with daily life

a) *Incongruent with daily life*
   i) Reported experience of unfit between previous service delivery models
   ii) -not meeting the needs of families
   iii) -inconvenient
      (1) "her OT at school spent the entire year working on fine motor stuff and okay, well it's not a waste of time, but to me it's not the most important thing"
      (2) "Her OT in IEP update said that there was no progress due to [my daughters lack of interests, I'm [thinking], who's lack of interest are we referring to?"
      (3) "with OT in the school district, you never know what they're working on. In outpatient, it's great, but you were there to be more hands on.

b) compatibility with daily life
"I liked [telehealth] in that I made my own goals and then we broke them down into steps that were really easy to implement"
"personally prefer [the telehealth OBC intervention] because I can try these strategies at home… [with telehealth] we tried techniques together and I would report to [the OT] how they went"

c) Convenience of the intervention
   i) -decrease travel and was more accessible for their family
"it's very difficult to go to offices and sit for an hour, get everybody out of the house and somewhere on time. so that was really convenient being able to do [telehealth] from home, and it only took an hour, it didn't take an hour plus travel time"
"I really liked that it was in our schedule"

"very customised to our life and our routine and how we did things. It was awesome, instead of being life 'here's this technique make it work for you'. It was 'what did you do? Oh, maybe we can improve upon that. Let's try a few different strategies"
"loved problem solving little issues we had throughout our week and how tailored or customized to our life it was"

2) Collaborative relationship

a) *Professional knowledge offered by the therapist*

"it can be helpful to have someone to talk to about challenges you have with your child, a professional who has some knowledge in the area and is able to give you positive praise as well as suggestions to help you problem solve"

b) *The way in which the therapist was empathetic and did not judge parent decisions*

i) "I feel like my opinion or whatever I said [the OT] respected and valued my input"

ii) "I felt comfortable asking [the OT] questions, 'what does this mean? And I didn't feel judgment from her, you know telling me I'm doing something wrong… you kind of get that a lot. We're always kind of nervous because we're trying out best, you're always hoping you're doing it right… so I feel working together as a team was probably my favourite part"

3) Parent empowerment

a) -Able to problem solve in new situation

b) -able to reflect on the situation and evaluate

c) -Feeling confident in trying new strategies

"Normally I would've been fretting…instead I sat down with my child.."
"The OT gave me the confidence to sit down with my child and figure out what my child wanted.."
"Getting him more involve in his care, which I think as a parent, we take care of our children, but sometimes we don't always involve them in the decisions, and for him that was a big deal"

d) Better understanding of their child's behaviour

"[telehealth] helped me to step back and take a deep breath and then look at it like, how can we learn from this, how can we do this different? How can we problem solve this?"

e) Changes in their perspective about their child's behaviours

f) Increased discussion with their children with greater positivity by mentioning child's strengths,

g) Increase patience with their child

"I am more patient with him because I realised that he's not doing anything wrong and we can problem solve and try different strategies to make something work."

APPENDIX C

Code Map

Table C.1

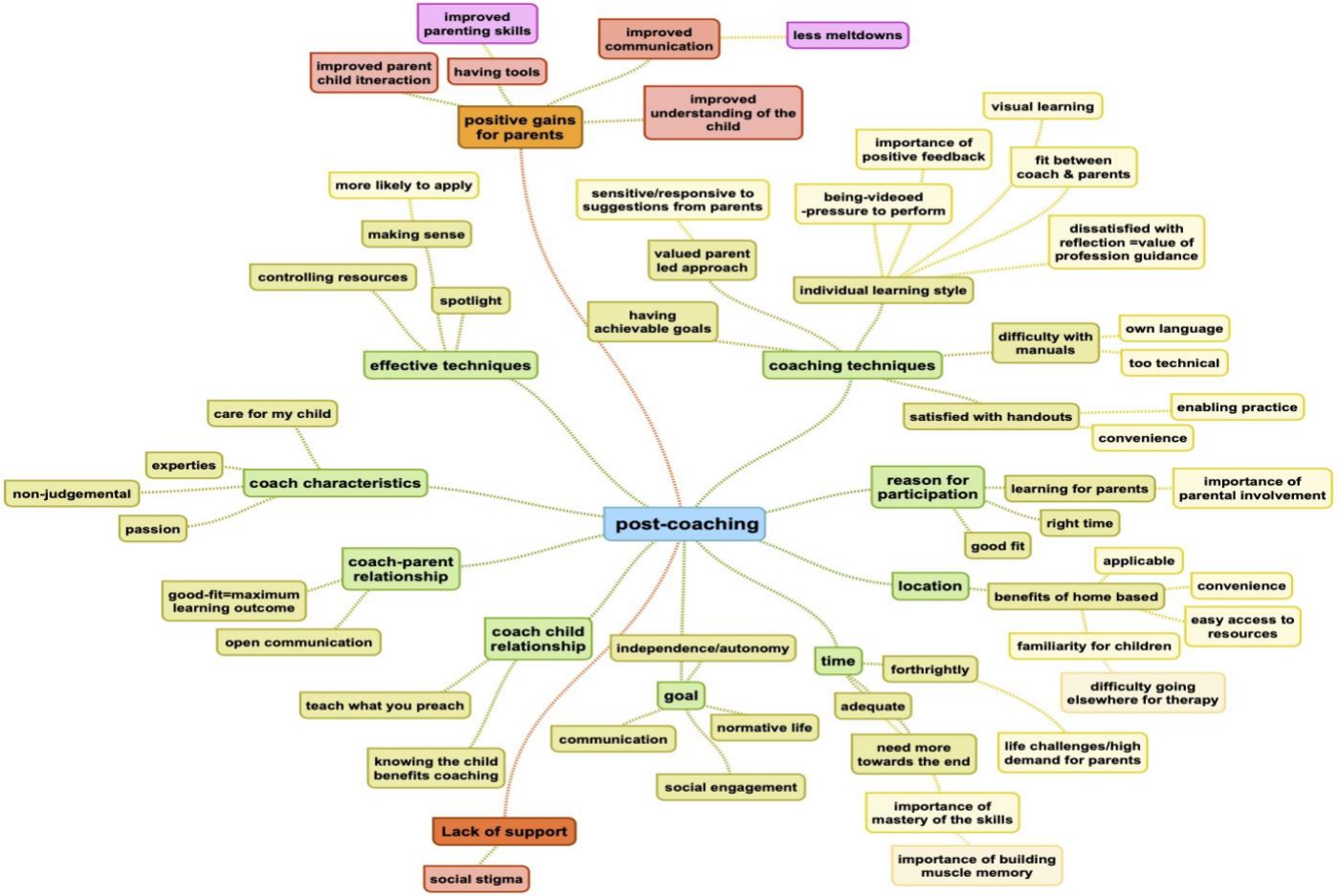
List of included studies and the location of the relevant codes

Codes	An (2017)	Brezis, et al. (2015)	Chlebowski , et al. (2018)	Cutress & Muncer (2014)	Donaldson, et al. (2011)	Foster, et al. (2013)	Freuler, et al. (2014)	Hodgson, et al. (2018)	Hodgetts, et al. (2013)	Patterson & Smith (2011)	Pickard,et al. (2016)	Rivard, et al. (2017)	Stahmer, et al. (2017)	Wallisch, et al. (2019)
Positive parent-therapist relationship			•			•								•
Valuing herapist expertise						•						•	•	•
Positive therapist characteristics			•			•						•		•
Easy accessibility and flexibility						•		•			•	•	•	•
Benefits of group format			•											
Difficulty finding time to read and practice							•	•		•		•	•	
Difficulty completing homework								•		•		•	•	
Scheduling incompatibility										•				
Unmet informational needs			•					•		•				
Unmet emotional neds	•				•			•		•				
Unmet service needs							•	•			•			
Increase in ASD Knowledge	•	•		•			•	•	•			•		
Increase in parenting skills	•			•	•		•	•	•					
Able to understand child better	•			•		•		•						•
Positive shift in perspectives	•	•		•		•			•					•
Reduced stress				•					•			•	•	
Improved sense of empowerment				•		•			•		•		•	•
Improved parent-child interaction	•	•			•						•		•	
Improve family quality of life				•							•			

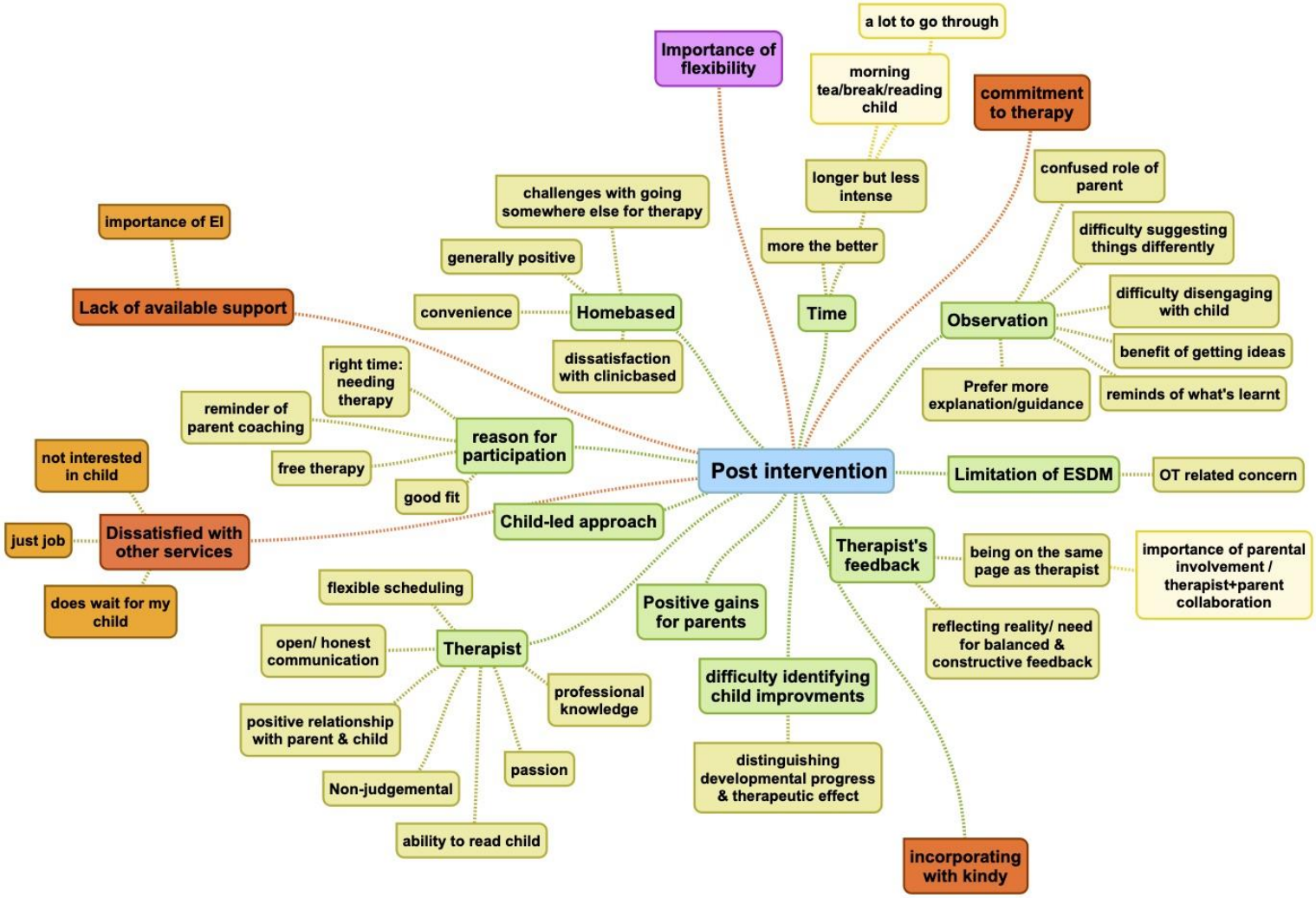
APPENDIX D

Code Maps

1. Code map parent-training interview



2. Code map for post direct-therapy interview



APPENDIX E

Interview Questions for Parent-training, Direct-therapy and Comparison

1. Post parent-training questions

Background

First, we are going to talk about about your child and your goals for your child

How old is [child]?

What are [child's] likes and dislikes?

What are your main goals for your child?

(i.e., what do you want them to acheive, from this intervention and more generally in their life? E.g. talk more, be happy)

Is there anything else that you want to share about your child?

Why did you want to participate in the parent coaching?

Parent coaching techniques

We are now going to talk about the way that you were taught to use the ESDM techniques techniques

What are your thoughts on the timing of the parent coaching sessions?

(e.g. 1 hour per week for 12 weeks)

Note: Select one or the other depending on response to previous questions:

What was it about the timing of the sessions that was helpful?

What was it about the timing of the sessions that was not helpful/challenging?

How could the timing of sessions be improved?

What are your thoughts on the location of the parent coaching sessions?

Note: Select one or the other depending on response to previous questions:

What was it about the location of the sessions that was helpful?

What was it about the location of the sessions that was unhelpful/challenging?

(e.g., disruptions, space, suitability of materials)

Would there be a more suitable location? If so why?

What are your thoughts on the techniques that [coach] used to teach you the ESDM strategies?

(e.g. practice, reflection from you, reflection from coach, direct teaching, handouts, discussion, weekly goal setting, reading the parent manual)

Which parent coaching techniques did you find particularly effective/helpful? Why?

Which parent coaching techniques did you find less effective/unhelpful? Why?

Do you have any suggestions in relation to how [Hannah] coached you?

ESDM strategies

Now we are now going to discuss the specific ESDM strategies that you used with [child] *(e.g. different strategies taught each week, from different chapters of parent ESDM e.g. capturing your child's attention, sensory social routines, object focused routines, the importance of non-verbal communication, ABCs etc...)*

Which ESDM strategies did you find particularly effective/helpful?

Which ESDM strategies did you find to be less effective/helpful?

Which ESDM strategies did you find easier to understand? Why?

Which ESDM strategies did you find harder to understand? Why?

Which ESDM strategies did you find easier to use with [child]? Why?

Which ESDM strategies did you find harder to use with [child]? Why?

Do you have any suggestions in relation to the effectiveness, clarity, or easiness of the ESDM strategies?

Child outcomes

What difference, if any, do you think the parent coaching has made for you and your child? *(e.g. play skills, communication, behaviour, interaction and engagement with others.*

In what areas/skills/behaviours have you seen the biggest changes/improvements in your child?

In what areas/skills/behaviours have you seen less or no improvement?

Relationship with the coach

Reflecting on your experience during this parent coaching: What personal traits, characteristics and skills do you think an effective parent coach needs to have? *(e.g., patience, enthusiasm, non-judgmental, professional, good communication etc)*

Were there any of these traits that you felt [coach] particularly demonstrated?

Were there any of these traits that you felt [coach] did not demonstrate?

Can you describe for me the relationship between the parent coach and you?

How important was this relationship to you and to your learning?

Could the relationship between the parent coach and you have been improved? How?

Can you describe for me the relationship between the parent coach and your child?

How important was this relationship to you and your child?

Could the relationship between the parent coach and your child have been improved? How?

Do you have anything else to add?

2. Post-direct therapy

Background

First, we are going to talk about about your child and your goals for your child

What are [child's] interests at the moment?

What are your main goals for your child?

(i.e., what do you want them to achieve, from this intervention and more generally in their life? E.g. talk more, be happy)

Is there anything else that you want to share about your child?

The following questions are just about the one-on-one therapy with [therapist]. So I want you to think back to those therapy sessions with [therapist]

Please try not to compare it with the parent coaching with [coach].

Why did you want to participate in the therapy?

Structure and parent involvement in therapy

We are now going to talk about how you found the running of the therapy sessions.

What are your thoughts on the timing of the therapy sessions?

(e.g. 2 x 1 hour per week for 12 weeks; Were they long enough? Were they frequent enough? Was there enough time between to practice?)

Note: Select one or the other depending on response to previous questions:

What was it about the timing of the sessions that was helpful?

What was it about the timing of the sessions that was not helpful/challenging

How could the timing of sessions be improved?

What are your thoughts on the location of the therapy sessions?

Note: Select one or the other depending on response to previous questions:

What was it about the location of the sessions that was helpful?

What was it about the location of the sessions that was unhelpful/challenging?

(e.g., disruptions, space, suitability of materials)

Would there be a more suitable location? If so why?How often did you stay to watch the therapy sessions?

Only ask if the parent did stay to watch the therapy sessions

What did you learn from watching the therapy sessions?

Was watching the therapy sessions helpful? Why?

Were there any aspects of the therapy sessions, if any, did you find less effective/unhelpful? Why?

Do you have any suggestions about watching the therapy sessions? Why? *(e.g., do*

parents need to pay particular attention to certain aspects of the therapy? Do they need to be told to watch how the therapist does certain things)

Did you get an opportunity to discuss the therapy sessions with the therapist? Y/N

If Yes: How often did you discuss the therapy sessions with the therapist?

Did you find these discussions effective/helpful? Why/Why not?

Do you have any suggestions about discussing the therapy sessions? Why? (e.g., do parents need to discuss certain aspects of the therapy? Do discussions need to be focused on deepening understanding? Clarification? Limitations)

<u>ESDM strategies</u>

Now we are now going to talk about the specific ESDM strategies that [therapist] used with [child]

(e.g. capturing your child's attention, sensory social routines, object focused routines, the ABCs etc...)

What were the techniques, if any, that you particularly noticed the therapist using?

Which ESDM strategies, if any, did you find particularly effective/helpful?

Which ESDM strategies, if any, did you find to be less effective/helpful?

Which ESDM strategies, if any, aligned best with your parenting values?

Which ESDM strategies, if any, aligned least with your parenting values?

Do you have any suggestions in relation to the therapists use of ESDM strategies?

Child outcomes

We are now going to talk about the impact of the therapy on your child.

What difference, if any, do you think the therapy has made for you and your child?

(e.g. play skills, communication, behaviour, interaction and engagement with others.

In what areas/skills/behaviours have you seen the biggest changes/improvements in your child?

In what areas/skills/behaviours have you seen less or no improvement?

Relationship with the therapist

Reflecting on your experience working with/alongside the therapist: What personal traits, characteristics and skills do you think a therapist needs to have to be effective? *(e.g., patience, enthusiasm, non-judgmental, professional, good communication etc)*

Were there any of these traits that you felt [therapist] particularly demonstrated?

Were there any of these traits that you felt [therapist] did not demonstrate?

Can you describe for me the relationship between the therapist and you?

How important was this relationship to you?

Could the relationship between the therapist and you have been improved? How?

Can you describe for me the relationship between the therapist and your child?

How important was this relationship to you and your child?

Could the relationship between the therapist and your child have been improved? How?

Do you have anything else to add?

3. Comparison between ESDM-based parent-training and low-intensity ESDM direct-therapy

The following questions compare the parent coaching with the one-on-one therapy.

Structure and parent involvement

How did you find the timing of the parent coaching sessions compared to the timing of the therapy sessions? *(e.g. 1x 1 hour per week= parent coaching; 2 x 1 hour per week= therapy)*

Which, if either, did you prefer? Why?

How did you find your involvement in the parent coaching sessions compared to your involvement in the therapy?

Which, if either, did you prefer? Why?

ESDM strategies

How did you find your use of the ESDM techniques, compared to the therapist's use of the ESDM techniques?

Which, if either, did you prefer? Why?

Child outcomes

Using ESDM, what impact do you think you have had on outcomes for your child compared to the impact the therapist has had on outcomes for your child?

Which, if either, did you prefer? Why?

Relationship with the therapist

How did your relationship with [coach] compare to your relationship with [therapist]?

Which, if either, did you prefer? Why?

How did your child's relationship with [coach] compare to your child's relationship with [therapist]?

Which, if either, did you prefer? Why?

Imagine you had not recieved either of these services: If you could only choose parent coaching or one-on-one therapy, which would you prefer? Why?

What else would you like us to know?